Participatory research to strengthen the role of patient and public involvement in general practice service improvement

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Abstract

Patient participation in healthcare organisational decision making is important internationally. Health policy rhetoric cites the moral rationale, but also claims participation will result in more patient centred services, despite little evidence. In English general practice, this policy is enacted through contractual requirements for every general practice to involve patients in service improvement through Patient Participation Groups (PPGs). However, there are problems with making this routine and meaningful for all stakeholders.

To address this policy-practice gap, this thesis describes participatory research to develop and field test an intervention to strengthen patient participation in general practice service improvement.

The intervention was designed and evaluated with a multi-stakeholder co-research group. We worked together to develop an adaptable prioritisation survey, based on a discrete choice experiment, and to design intervention meetings emphasising partnership working. This process was supplemented by data from focus groups and pilot testing of the prioritisation survey. Normalisation process theory was used to design and evaluate the intervention, focusing on the work of meaningful participation. The intervention was field tested in two general practice PPGs. Over the period of one year we facilitated the intervention and conducted a qualitative evaluation. Prioritisation surveys were conducted in both sites and analysed quantitatively.

The intervention combined two participatory mechanisms: *partnership working,* and *consultation*. Combining these mechanisms enhanced opportunities for credible knowledge exchange, legitimate representation, and addressed power. Field testing sites adapted and implemented the prioritisation survey, and made patient centred action plans based on the results. We identified and developed a framework of the work of creating and maintaining an inclusive, equitable, and safe participatory space for shared organisational decision making.

The intervention resulted in actions consistent with patient priorities for service change. There is a clear need to recognise and resource the work of creating and maintaining participatory space.

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Abbreviations

BIC	Bayesian Information Criteria
CI	Co-operative inquiry
CRG	Co-research group
DCE	Discrete choice experiment
EBM	Evidence Based Medicine
ENPT	Extended Normalisation Process Theory
FG	Focus Group
GP	General Practitioner
GPPS	General Practice Patient Survey
ICPHR	International Collaboration for Participatory Health Research
MRC	Medical Research Council
MREC	Medical Research Ethics Committee
NHS	National Health Service
NIHR	National Institute for Health Research
NPT	Normalisation Process Theory
PAR	participatory action research
PCN	Primary Care Network
PLA	participatory learning and action
PM	Practice Manager
PPG	Patient Participation Group
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
TAFG	Task and Finish Group
TIDieR	Template for Intervention Description and Replication
TTO	Time Trade Off
UK	United Kingdom
USA	United States of America
WTP	Willingness to Pay

1. Introduction

Patient participation in health care design and delivery has been promoted and supported internationally for over half a century.(1-4) In the UK, it has been supported by successive governments and is now enshrined in the NHS constitution.(5-7) Enactment has been supported by regulatory and legal frameworks, including the contractual requirement for every general practice to engage with patients through Patient Participation Groups (PPGs).(8, 9) Despite this, the terminology, meaning and purpose of patient and public involvement, engagement, and participation, are contested and variably interpreted.(3, 10-12) Health policy recognises patients' rights to be involved, and discusses the importance of participation for governance, safety, accountability, innovation and quality.(5, 6, 13) However, findings from separate inquiries into systemic NHS failures from 2013 to the present, have concluded that patients' concerns are still not listened to or acted on, and existing institutional mechanisms for involving patients have failed.(14-17) Therefore, in 2015 NHS England called for services to "*engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services*."(13)

Patient participation could be conceptualised as a complex intervention, involving multiple interacting and often social components, that has the potential to improve patient care by increasing patient safety, encouraging patient centred services, fostering accountability, and improving patient experience. To avoid wasting resources on dysfunctional interventions, the theoretical and practical components of complex interventions require delineation and development prior to summative evaluation.(18) **This thesis reports the work of a National Institute for Health Research (NIHR) Doctoral Research Fellowship to design and field test an intervention to strengthen the role of PPI in general practice service improvement using participatory research.**

This chapter provides an overview of patient participation in general, before focusing on patient participation in general practice through PPGs, and the current challenges this poses. I will then briefly outline some of the attempts to strengthen patient participation in general practice in other countries which have influenced this research. Finally I will outline the aims and objectives of this thesis including an outline of the intervention we developed during this research.

1.1 Definitions and models of participation

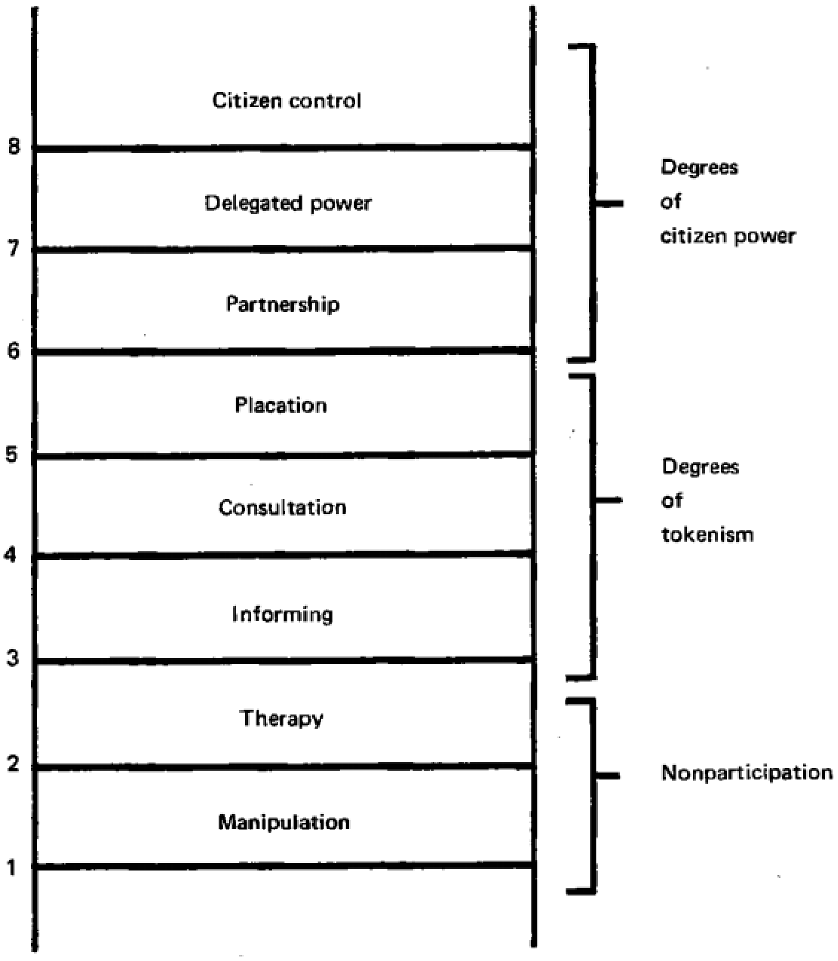
There is an ever increasing international evidence base related to patient participation. One recent systematic review of reviews identified 42 existing systematic reviews.(3) This literature covers a plethora of terminology for the actors: patient, the public, citizen, user, and consumer, as well as activity: involvement, engagement, participation, knowledge transfer, deliberation, co-production and co-design.(19) Often these terms are used interchangeably, and are not defined or rationalised.(12) This has resulted in overlapping and confused participatory policies with lofty aims, which continue to be promoted despite little evidence of impact.(12) Therefore there is a need to be clear about meaning and rationale of patient participation. **I use the term 'patient participation'.** 'Patient' is an increasingly contested term due to the connotations of passivity.(20) However, this thesis is focused on the participation of people in general practice services, and common nomenclature still addresses people in this setting as patients. I use the term 'participation' because it is an active noun implying agency. This is in comparison to involvement and engagement which suggest passivity and the requirement of a second party to involve or engage an individual. Participation has multiple and contested meanings that will be explored below. The term 'patient participation' is sometimes used to refer to patient-clinician interaction within a consultation, often sharing decisions about investigations and treatment options.(2) This thesis is solely concerned with patient participation in organisational decision making in general practice settings either directly, or indirectly through participating in research on this topic. Equally this thesis is focused on the process of participation, where, when, and how this happens and the social norms that influence relationships, interactions and power, rather than the process of shared decision making. There is a vast literature on shared decision making, how and why people make decisions, and the factors that influence these decisions. Participation is a pre-condition for sharing decision making, and therefore important and worthy of separate investigation.

From the systematic reviews in this field it is clear that the broad evidence base covers: participation in healthcare (21, 22) and research about healthcare (23, 24); multiple medical specialities including general practice (4, 25), public health, and social care (3); and small-scale (one general practice (26) or hospital ward (27)) to large scale (health policy (28) and service reconfiguration (29)), with everything in between. The evidence base cuts across disciplines incorporating health service research (3, 21, 22, 30), sociology (31), health policy (32), public administration (33), economics(34), and development (35, 36). Frequently occurring themes in the evidence base include: ill-defined and inconsistent terminology, purpose, and values (3, 4, 25, 37, 38); power differentials between stakeholders (3, 24, 39-41); representation, diversity, and inclusion (3, 42-45); the importance of context and the influence of individual, organisational, and systemic factors (24, 25, 46, 47); and the subjective nature of involvement and the resulting difficulty in measuring impact, especially within an evidence based framework (24, 48, 49). Many of the reviews also comment on the poor quality of studies, especially the reviews focusing on participation in healthcare design or delivery.(3, 22, 30) There is a spectrum covering the majority, simple descriptive ‘how to’ or ‘what we did’ case studies often with glowing results, to the minority, conceptually rich critical evaluations resulting in theory generation.

One entry point to exploring this vast literature is through models and typologies of participation. Below I will summarise the three models, from Arnstein, Dean and Cornwall,(33, 36, 50) that are most relevant to this thesis, but as with the rest of the literature there are a vast and increasing number of models, frameworks and typologies.(11, 35, 51, 52) What the three models have in common is their inception in response to the complex, heterogeneous, and often confused multiple meanings of participation. Arnstein developed her ladder in response to tokenistic rhetoric, highlighting that not all modes of participation are equal and redistribution of power is the key.(36) Dean’s typology aims to highlight the different underlying social and political philosophies of participation including knowledge transfer, efficiency, empowerment, and governance and accountability.(33) Cornwall uses the concept of participatory space to highlight the social, structural, and temporal influences on participation.(50) Other authors have chosen to explore the evidence by reviewing mechanisms of participation.(53, 54) However, all three models below concur that similar participatory methods and mechanisms may be used across modes of participation for completely different purposes.(33, 36, 50) Therefore, it is essential to understand the purpose of participation in order to understand and evaluate the positive and negative effects of participation.

The most famous typology is Arnstein’s ladder of citizen participation from 1969.(36) Arnstein took the explicit stance that participation is the cornerstone of democracy, and participation without redistribution of power is tokenism: *“citizen participation is citizen power”p216*.(36) Her ladder classifies participation from the perspective of the disempowered citizen and their potential to influence institutional decision making (Figure 1.1). The ladder is an explicit hierarchy with the normative assumption that participatory practices at the top of the ladder are better than those at the bottom. The bottom rungs describe non-participation practices including therapy and manipulation. The middle rungs describe tokenistic participation where the elite consult, inform, or placate the disempowered citizen. The top rungs describe citizen power through partnership, negotiated delegation, and control of decision making by empowered citizens (Figure 1). She acknowledges that the ladder is an oversimplification, designed to focus on the differing practices of participation, exposing the rhetoric that all participation is transformative. She accepts that the ladder positions powerful elites against the disempowered. She recognises these groups are not homogenous, but also that they perceive each other to be homogenous groups. She highlights that both groups create barriers that prevent participatory practices at the top of the ladder. The elites display racism, paternalism, and resistance to redistribution of power. The disempowered lack socioeconomic infrastructure, knowledge, and organised collective accountability due to ongoing futility, alienation, and distrust. Arnstein's ladder has been criticised for being too simplistic and overly focused on power.(55) Tritter and McCallum argue for a broader definition of participation that includes volunteering and other skills, assets, and resources that the public contribute beyond decision making. Despite this power remains an important topic within the participation literature and Arnstein's ladder is still relevant and broadly referenced over 50 years on.

Figure 1.1. Arnstein's 8 rungs of a ladder of citizen participation.(36)



Dean recognises that citizen participation in social policy decision making has multiple meanings, with Arnstein's transformative participation being only one of them.(33) He highlights the support participation policies receive from all political parties across the political spectrum. Therefore, Dean's typology of participation aims to move beyond normative assumptions of 'good' or 'bad' participation that feature in Arnstein's work, and critically situate forms of participatory practice within wider social and political theory. The focus of his typology is on 'legitimate' participation, which he defines as a means of public influence or decision making recognised as such by reasonable people. Therefore, he does not include non-participatory practices such as manipulation, and he does not include volunteering. Dean describes two dimensions of participation: sociality, whether individuals and groups are working for the common good (solidaristic), or their own positions and values (agnostic); and negotiability, whether the conditions of participation are negotiated or prescribed. This results in four modes of participatory decision-processes (Figure 1.2 and Table 1.1). Dean argues that his typology should be used sensitively to understand the underpinning philosophy of different participatory approaches, conflicts between stakeholders, evaluations of participatory initiatives, and differing outcomes of similar participatory mechanisms.(33, 56) He describes how mechanisms can be used within different modes, for example citizen juries have been used for knowledge transfer, arbitration, and deliberation as part of collective decision making. Finally he argues that the increasing move towards multi-level governance, with the recognition of heterogeneous publics, creates the need for "complex participatory systems" with interacting modes of participation.(28, 33) This would mean providing different opportunities for participation such as deliberative knowledge exchange, shared decision making based on this deliberation, and opportunities for the public to hold institutions to account for acting on the decisions.(28, 33) In a large system such as the NHS these modes might happen in different spaces with different people within the same system.

Figure 1.2. Dean's four modes of public participation in policy decisions.(33)

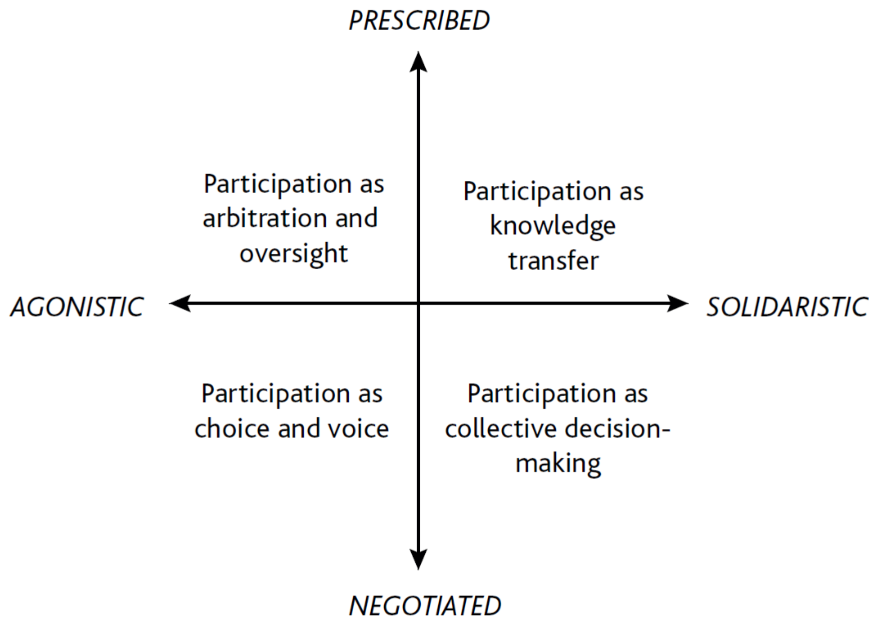


Table 1.1. Dean's four modes of public participation in policy decisions.(33)

Mode	Rationale	Enactment
Knowledge transfer	Decisions should be made on, and for the general interest of the population. Participation is a means of understanding the general interest of the population which is then used in decision making. The public are experts by experience and should be included in decision making as other experts are. The public are valued for their knowledge, not their judgement.	The public contribute as knowledgeable partners, but do not have power over decision-making. Often seen in institutional settings with predetermined agendas and prescribed processes of participation. Bargaining, strategic game playing, and negotiation are discouraged as the decision making is outside public control.
Collective decision making	Equal power for all in every decision making process. Five principles: (1) direct participation of all, (2) equal power, (3) decision making at the lowest appropriate level, (4) participation is part of everyday life, (5) participation is educational.	Participation is based on mutual respect and the common good. Aiming for consensus and mutual understanding, rather than conflict. Rules, inclusion, and content all negotiated and mutually agreed.
Choice and voice	Collective individualism. Individuals are rational decision makers aiming to maximise their own interests/utility. Participation is via individual choice, based on individual preferences. Services compete for customers based on their preferences, therefore customers indirectly shape decisions about services.	Competition via public sector markets. Public services collect and respond to customer preferences and complaints, to understand and meet demand. Interactions are between the service and the individual, rather than between citizens. Individuals decide their own preferences.
Arbitration and oversight	Decision making should be transparent and legitimate. The state is not unbiased or impartial. The public participate as an unbiased adjudicator (arbitration), or an impartial critic (oversight). Who participates and who controls this is of central importance, as it can be seen as an attempt by the state to exclude voices, or control the outcome.	Random selection attempts to limit involvement of vested interests. Public participation is often used to give legitimacy to a decision making process involving entrenched positions. The rules and agenda are decided prior to participation. Participation is adversarial and the resulting decision is enforced.

Cornwall invokes the idea of participatory spaces.(50) Space has properties which are physical, social, and temporal.(57) Spaces are flexible and may change in size, shape, and composition over time.(50, 57) Cornwall draws on sociological theorists including Habermas, Bourdieu, Foucault, and Lefebvre to argue that spaces are created by actors that inhabit them and the complex networked social relationships between actors within a space.(50) These relationships and resulting spaces are shaped by the politics, history, and actions of the space. Participatory spaces have fluid boundaries, change over time, and in response to other connected spaces. Participatory space exists through actors inhabiting the space, and the relationships within the space only exist because of the space. Therefore, as Dean suggests, it is essential to understand the political philosophy of the space which shapes relationships within it.(33) It is equally important to focus on the social relationships, and particularly power, that Arnstein suggests, organise the space.(36) Cornwall identifies four clusters of participatory space with similarities in terms of inception and durability (Table 1.2).(50) She describes inception of spaces as either invited or emergent. Invited spaces are resourced and designed by an external authority who invites ‘other’ people into the space and suggests how they behave. Emergent spaces are organic collectives of people with common interests and goals who negotiate their own rules and behaviours. The focus on invited versus emergent spaces is similar to Dean’s negotiated versus prescribed modes of participation, but with more focus on agency. Durability describes the temporal nature of the space which she describes as transient or regularised. Similarly to Arnstein and Dean, Cornwall argues that similar participatory methods may be (mis)used across these different clusters of spaces. Cornwall, argues that there needs to be increased attention to the architecture of the space and the resulting micro politics of agency and power within the space and shaping the space.

Cornwall, like Dean, does not suggest one cluster of spaces is better than another, but that they are different and provide different opportunities and constraints on heterogeneous publics to have influence over decision making.(50) In later work Cornwall argues for pragmatic over idealised forms of participation.(35) She acknowledges that pragmatic participation involves political decisions about the participatory space, influenced by other connected spaces. She describes purpose and breadth as further dimensions of participatory space. Participation may be instrumental, a means to achieve a defined goal such as patient centred services, or transformative, a goal in its own right. One is not necessarily better than the other. Instrumental processes can be transformative, and transformative processes may be subverted or ignored if the powerful are not involved. Cornwall argues participatory spaces can be wide or narrow depending on who participates. She argues it is impossible to involve all people in all decisions, therefore key questions are who will be involved and who is absent, how will they be involved, and who will decide? She also highlights citizens' agency to choose not to participate. Cornwall argues that the most important aspect for pragmatic participation is transparency and providing multiple options for participation which can be chosen (or not) rather than enforced.

Table 1.2. Cornwall's clusters of participatory spaces.(50)

Cluster	Characteristics	Description of the space
Regularised relations	**Invited regular spaces.** Institutions invite the public to participate regularly with the aim of improving the institution.	The public have limited power. If it exists, it is predefined and bestowed by the institution. Opportunities to participate are restricted to deliberation between chosen 'representatives'. A key issue is who selects the representatives. These spaces can provide opportunities for relationships to develop which may create new spaces for influence.
Fleeting formations	**Invited transient spaces.** External policy making organisations (state institutions or those acting on their behalf) invite the public to short term spaces to give their view, which may or may not be taken into account.	The content and form of the space is predetermined and bounded. Traditional consultation or participatory methods used to encourage deliberation rather than decision making. Who is invited depends on the purpose and those doing the inviting. Selection may be based on broad or defined spectrums of the public. These spaces may open up opportunities to a wider public, but there is little evidence of influencing policy.
Acting as, acting on, acting up: alternative interfaces	**Emerging regular spaces.** Advocacy groups or groups modelling alternatives to the state (includes voluntary and community sector) provide reoccurring spaces outside and autonomous from the state.	These spaces can be radical or established, and may be trying to change the state. The public choose to participate rather than being chosen or invited. As a result they attract likeminded individuals resulting in a collective voice which may claim to speak on behalf of a particular public. This may have an inclusive and empowering, or exclusive and disempowering effect on others. The demand to participate maintains the space.
Movements and moments	**Emerging transient spaces.** Popular protest, public campaigns, complaints and expressions of voice.	These are fluid, flexible, and spontaneous spaces which are ill defined and uncontrollable. They are places of resistance and challenge. They may develop critical mass around a common purpose, but are rarely inclusive of diverging perspectives.

These three typologies highlight the multiple interpretations of participation and the effect that this can have on the practice of participation. Arnstein draws attention to how the powerful can subvert participation through tokenistic practices.(36) Dean broadens the scope of participation to include how both individuals and groups can exert influence for themselves and others in both invited and self-created spaces.(33) Cornwall reminds us that these political and social influences that create or enable the space, shape the relationships within the space and the opportunities for transformative change.(35, 50) They all agree that typologies can oversimplify what is a complex practice rooted in context and rarely simple. All three call for critical interrogation of what people participate in, for what purpose, and who participates (or not).

1.2 Participation and the NHS

Successive UK governments have enacted policies directed at participation in the NHS.(10, 33, 38) One review traces the origins of participation in health policy, to the early 1990s NHS reforms resulting from a perceived lack of trust in NHS governance.(38) Since then, there has been continuous evolution of policy regarding NHS patient participation as a result of changing governments and successive NHS reforms.(10) This has resulted in a plethora of initiatives and mixed participatory spaces, with different actors, rules, and goals that have changed shape over time.(33) Table 1.3 outlines the current participatory initiatives and spaces which have some influence on English general practices and how they relate to the three typologies of participation described above. What these spaces have in common is that they are mostly invited spaces, with the terms of participation controlled by the NHS. Patient Participation Groups (PPGs) are one of these invited spaces that have particular features due to being invited *regular* spaces which are continuous over time.

Table 1.3. NHS participatory spaces which may influence general practice

Space or policy initiative	Description and rationale
National choice and/or voice policies.	National *choice and/or voice* policies promoting participation have been enacted by successive governments since the 1990s.(33, 38) The aim was to improve the NHS through stimulating competition and hence choice between different services, including general practices. This included the introduction of the national General Practice Patient Survey (GPPS) and the annual publication of results to encourage patients to participate individually by choosing ‘better’ general practice organisations.
Statutory arm’s length organisations	Healthwatch was introduced as part of the 2012 NHS reforms (prior to this similar organisations were promoted) and is described as the ‘NHS consumer champion’.(47) It is a statutory arm’s length institutional body which acts both on behalf of the NHS (*invited space*) and outside the NHS

such as Healthwatch.	(*emergent space*). Its mode of participation is *oversight and arbitration*. It has statutory powers to hold general practice 'enter and view' inspections. However, much of its activity focuses on public *consultation* and reporting back to NHS institutions, with little direct decision making power.
Roles for individuals such as PPI representatives in clinical commissioning groups.	Roles within NHS decision making or commissioning organisations where individuals are invited to take part in *regularised relations*. Individual roles are formal with pre-defined rights and responsibilities, such as being an 'independent' chair for a specific meeting (often chairing primary care quality meetings in clinical commissioning groups). Their rationale is *arbitration and oversight*. There are considerable questions about diversity and their role as 'representatives'.(43, 44, 58) There is some evidence of individuals using these spaces to create connected spaces of transformative possibility.(57)
Pre-defined co-production and co-design space with pre-defined purpose.	Co-production and co-design are positioned as more equal '*partnership'* participation.(59-61) Both are *fleeting formations*. Patients are invited to work *with* professionals in one off or short term pre-defined projects to produce or design service improvements. They are *knowledge transfer* modes of participation: patients are experts by experience which is valued alongside professional expertise. It has been questioned whether co-production and co-design are transformative or instrumental, aiming for increased effectiveness and efficiency.(39)
Spontaneous and self-organised space for campaigns or direct challenge	The only approach outside NHS institutions. Direct challenge through individuals or groups complaining or campaigning to influence NHS decision making, including general practices. This is Cornwall's *movements and moments* cluster of spaces. Individuals and groups work outside the NHS and set their own rules. Cornwall argues this type of participation can be (and is) ignored by those with decision making power.(14-17, 50) National examples include patient campaigns about the quality and safety of services at Mid Staffordshire NHS Foundation Trust resulting in the Francis Inquiry, and more recently campaigns resulting in inquiries into maternity services, medicines management, and breast surgery.(14-17)
Organised public consultation spaces	The NHS has statutory obligations to hold formal consultations on specific changes, including closing a general practice.(10) These spaces are *fleeting formations*: invited transient spaces with formal rules and processes. The mode of participation depends on the organisational culture.(29) This includes adversarial *arbitration and oversight*, *collaborative knowledge transfer*, or *non-participatory educational approaches*. Depending on the local context, there is often overlap with local campaigns and protests to keep services open.(50)
Poorly defined mandated intra-organisational space such as Patient	General practices invite their registered patients to a regular participatory space. PPGs have been described as an acceptable 'off the shelf' solution to multiple participation policies.(25) Early adopters valued a rights based collective decision making rationale: participation transforming community health and reducing inequalities.(1, 62) Later

Participation Groups (PPGs)	policies were instrumental in promoting PPGs as a form of consumer feedback, choice and voice rationale, or to stimulate service improvement via knowledge transfer.(38) In 2011, general practices were incentivised to establish PPGs, before making them a contractual requirement in 2015.(8, 63) This change moved the space towards arbitration and oversight, in response to GPs new commissioning powers.(64) Despite the mandate, there is little guidance about the form or function of PPGs. The only contract specifications are that practices involve a representative group of patients in service improvement.(8)

Of all the participatory spaces in Table 1.3, PPGs are the space most closely aligned to general practice and the only one located within general practices. Therefore, this thesis focuses on PPGs.

1.3 Patient Participation Groups evidence base

Since their inception in the 1970s, PPGs have been underpinned by numerous rationales, as described in Table 1.3. However, there has been little critical interrogation of their function, purpose or impact. There is a small literature on PPGs published in waves since the 1980s. This literature was identified through a Medline search using keywords, and forward and back citation tracking to identify relevant papers. No limits were put on study design and no quality assessment was undertaken. The literature includes: local and national surveys regarding who participates (patients and practices), and the form and function of the PPGs (26, 65, 66); descriptive case studies of PPGs (67, 68); interviews and focus groups with patients and staff about PPGs (62, 64, 69-71); and descriptive reviews of the evidence and policy literature (25, 38, 72, 73). Only one study aimed to investigate the impact of PPGs. Greco et al conducted a small randomised controlled trial to investigate whether the introduction of PPGs improved patient experience.(74) The trial showed no effect, but the follow up period was short, and a process evaluation did demonstrate patient centred improvements in practices with PPGs. Most of this literature evaluates existing PPGs, and is of limited quality. No studies have observed what actually happens in PPG meetings, except for a small pilot study in advance of this fellowship (Appendix 1).(75) Despite this limited evidence base, financial incentives were introduced in 2011.(6, 63) These incentives increased the number of PPGs, with an estimated cost to the NHS of £80 million between 2011 and 2015 and with uncertain impact.(71, 72) A number of themes emerge from this literature about the challenges PPG face. These themes are role confusion, representation, and power dynamics and are discussed below with reference to the wider participation literature.

1.3.1 Role confusion

Multiple studies cite role confusion as a barrier to effective PPGs.(25, 64, 70, 72, 73) National surveys of practice managers and PPG members between 2005 and 2008 demonstrated that the most common PPG activity was representing the patient perspective.(65) However, they also reported a broad variety of less common activities such as volunteering, peer support, and fundraising. There are a wide variety of forms and formats of PPGs, which were generally seen as critical friends with a supportive but subservient role to the general practice.(68) Most PPG activity involved collecting feedback, most commonly regarding single issue projects suggested by the practice.(68) In the 2008 survey only 44% of active PPG members described their groups as influential, and there were considerable concerns that financial incentives would result in limited and potentially tokenistic PPG roles.(65)

Three studies explored PPG roles following the introduction of financial incentives.(64, 70, 71) All found that the primary role of PPGs was still representing the patient perspective.(64, 70, 71) Patients participated in designing, distributing, and reviewing surveys, and prioritising action plans for service improvement with staff, all requirements of the financial incentives.(71) However, the studies also suggest there are a number of concerns about the roles of PPGs following the introduction of incentives. A minority of PPG members are unsure of the purpose of their PPG, suggesting tokenism.(70) PPG members struggle to define ‘quality of care’ and limit discussion to topics they know about such as the waiting room and appointment systems.(70) PPGs mainly discuss non-clinical services and are reluctant to discuss clinical decisions.(71) There are a wide variety of formats of PPGs, from patient to practice led, and virtual to face-to-face, increasing confusion about role and purpose.(64) Some patients felt the financial incentives increased practice accountability, whilst others felt it added unnecessary formality to their PPG.(71) Different patients had different opinions about the level of their participation, some only want to receive information.(71)

Evidence suggests individuals choose to participate in organisational decision making, including PPGs for different reasons and want different levels of participation.(76) The most common type of desired participation is an “over-seeing” role, working in partnership with an organisation. Patients rarely want responsibility for decision making, rather they want to be consulted and listened to.(77) However, not all patients agree about their expectations of participation, or their role.(76) Our pilot identified six roles PPGs enact: the interested citizen, looking for information; the innovator, aiming for service improvement; the community developer, interested in volunteer and peer support activities; the governor, aiming to hold the practice to account; the representative (see below); and the supporter, aiming to support the NHS.(75) Other authors agree that role conflict and active non participation occur in all settings when different individuals in groups, both patients and staff, have different expectations about their roles.(25, 71, 75) This can lead to non-functioning and ineffective PPGs. Different preferences for participatory approaches and roles are linked to individuals' (patients and staff) identities, interests, and values.(69, 78)

1.3.2 Representational legitimacy

The current national GP contract states PPGs must be representative of the practice population.(63) All the evidence suggests that PPGs struggle with recruitment, diversity, and sustaining membership.(26, 65, 70, 71, 73) PPG coverage increased from 5% in the 1990s,(66) to 40% in the 2000s, mostly in rural or semi-rural locations, (65) to near universal coverage in 2010s.(64, 71) In 2007 over 70% of practices were interested in setting up a PPG, but had not done so due to time pressures, lack of skills, lack of patient interest, *"fear that the wrong patients will be interested",* and a sense that the practice already knows the patient population.(65) Evidence suggests financial incentives increased the number of PPGs established, but not the depth of participation.(65, 71) Only one 1985 study has investigated the sustainability of PPGs.(79) The authors found a quarter stop functioning after one year and the majority after five years. GPs blamed a lack of patient interest and low socio-economic status populations.(79) Other studies have argued that in order for any patient participation to be sustainable it needs adequate funding and skilled facilitators, especially in inner city areas.(71, 75, 80)

There is little up to date evidence about who attends PPG meetings. In 1991, one practice surveyed all adult patients (73% response rate).(26) Only 45.1% of patients were aware of the PPG and only 7% had ever attended a meeting. Patients who had attended meetings were older, female, of higher socio-economic status, involved in other volunteering activities, and frequent users of services. A 2014 study estimated less than 1% of the population participate in PPGs.(71) Patient recruitment to PPGs mainly happens within practices via advertising within the waiting room (e.g. posters), or individuals being directly invited by a staff member.(71, 75) There is some evidence of practices recruiting through other voluntary and community sector organisations, but this is limited.(71) Online PPGs are frequently cited as an opportunity to increase participation and diversity, especially by younger patients, however, there is no evidence for this.(64, 71) The majority of groups include staff members, most commonly practice managers, although some are patient only groups.(70) This may contribute to the focus on non-clinical service improvements within PPGs. There is little evidence about the role of staff.

Both patients and staff recognise that PPGs are not representative of the wider patient population, and that this is a key weakness given their main function is representing the views of the public.(65, 70, 71) Our pilot observed that PPGs spend a large proportion of their time discussing recruitment and how to be more representative.(75) Attempts to rectify representation involve recruiting more participants, waiting room events, and surveying the wider patient population.(65) However, feedback surveys are problematic in themselves. There has been a steady increase in the amount of patient experience data collected within the NHS through formal annual patient experience surveys, such as the General Practice Patient Survey (GPPS), and the less formal, but mandated Friends and Family test.(81-83) This appears to be in response to national policies to improve services through choice and voice. Evidence suggests that the majority of effort is exerted on collecting and counting the number of patient responses, which is often incentivised, rather than analysing and acting on the content.(81, 84-86) This results in an industry of collecting data, but little service improvement. Some authors have called for more focus on using the data, moving toward a knowledge transfer rationale.(82, 84) Epistemic injustice has been cited as the reason why patient experience data is not acted on.(59) Epistemic injustice refers to the diminution of certain knowledge, in this case patient experience, by those in power, in this case doctors and the institutions they inhabit.(87) This corresponds with evidence that GPs don’t act on patient experience data because they view it as subjective, emotional, unrepresentative, not scientifically rigorous, and not specific to their local context.(83, 86, 88, 89) It is very rare that patients are involved in analysing or interpreting routinely collected survey data.(74, 84) Instead PPGs often conduct their own surveys which are even less formal and rarely scientifically valid or rigorous.(68, 75)

Within PPGs there are also issues about what is meant by being representative, with confusion regarding whether the role of PPG members is to represent their own views or the views of the wider population.(70) Representation is a key topic in the wider patient participation literature. Rowland and Kumagai describe three forms of representation (90):

- Democratic representation: based on ideas of rights and responsibilities and enacted through nominations and elections.
- Statistical representation: based on positivist notions of a representative sample and an ‘average’ patient who represents other people who have the same demographic characteristic.
- Symbolic representation: a subjective form of representation: *“a feeling, an impression, an experience, or a subjective belief”*. The authors liken this to the

individualistic interpretation of art, acknowledging subjectivity in how representation and impact are interpreted.

The contractual requirement to have a representative sample of patients, suggests the aim is for statistical representation, with little emphasis on whether those involved have the skills to contribute a wider view than their own. This is consistent with Dean's choice and voice mode of participation.(33) Other authors have claimed there is no such thing as an average citizen.(78) Martin argues that evidence persistently shows attempts at democratic and statistical representation fail, due to practical resource constraints and the underlying philosophy that populations with similar demographic characteristics have the same homogenous views.(43) He argues that a more important aspect of representation is the link between representatives and their constituents, and the skills and ability of the representatives to reflexively and competently represent their constituents' views within institutional decision making processes. This aligns with Dean's mode of participation of knowledge transfer: patient representatives are seen as experts in the experiences of ordinary people.(47) However, this mode of participation requires that representatives are chosen for their skills, and the emphasis returns to who chooses them, why, and who is not chosen.(35, 50) Elsewhere, Martin suggests that the implementation of policy directives mandating statistical representation, such as PPGs, is driving conflict in the practice of participation between different stakeholders with different interpretations of representation.(44) He found that staff identified representatives as biomedical statistical representatives with lay knowledge, while public representatives identified themselves as knowledgeable citizens.

1.3.3 Power dynamics

A number of studies highlight the limiting effects of power between PPG members and staff,(64, 68, 70, 71) and a smaller number between patient PPG members and the wider population.(65, 70) In other settings power hierarchies between staff have been found to affect patient participation.(58) There is evidence of practices appropriating PPG meetings to ameliorate complaints by sharing information about why change is not possible, patients find this frustrating.(64, 71) Some authors suggest this might be a tactic by the practice to avoid change.(71) Other authors have suggested policy makers, including general practices, only present options for change which are already planned.(31, 43, 68) Some PPG members are aware that their activities are limited by the practice, acknowledging their status as 'invited' participants.(70) One study suggested hesitancy to discuss clinical aspects of care may be due to socio-cultural issues surrounding the patient-doctor relationship, limiting patients' ability to question clinicians' judgement.(71) This has been described as a potential conflict of interest if patients are expected to hold their individual doctor to account on practice or system wide issues.(73) PPG members agreed that they sometimes struggled to balance their status as preferred PPG patients with holding the practice to account.(70) However, Box suggests that recruitment might improve if PPG members are attributed increased status.(65) Evidence in other settings suggests participation increases confidence, social capital, and empowerment of those participating, sometimes enabling unintended transformative opportunities.(57, 65, 67, 80, 91) However, there is no evidence of community empowerment via PPGs.

There is little research about the experience of and attitudes towards PPGs by general practice staff. Interviews in 1980 with GPs concluded that those who had PPGs were generally positive, but had long established views about the importance of patient participation.(62) Those who did not have PPGs were sceptical about the origins and functions of PPGs and appeared concerned that they may affect their autonomy and social status.(62) Professionals' definitions of patient participation are influenced by their roles and identities, which for GPs include clinicians, entrepreneurs,(69) and decision making bureaucrats.(92, 93) Tensions between roles can affect views about professional or lay control of PPGs.(69) Patient participation is linked to organisational culture.(67) A supportive, sharing general practice culture was an essential feature for successful PPGs.(74) However, many general practices do not have a culture of listening to or valuing patients.(68, 70) GPs hold the power to shape the participatory culture in general practices, although this is also influenced by resource availability.(67) Practices which prioritise team work and a whole person approach to care, embraced patient participation.(67) Practices where staff worked in silos and employed a biomedical or financially efficient approach to care, rejected patient participation. Patients were aware of and could identify cultural differences in the atmosphere of the practice and their clinical relationships. Public participation within large scale reorganisation is also shaped by organisational culture which then shapes the relationship between the organisation and the public.(29) Professional agency and organisational readiness have also been identified as important factors in whether or not patient feedback is acted on in hospitals.(27)

The above evidence demonstrates that patient participation in PPGs is controlled and shaped by the general practice staff who choose who is invited, and the terms in which patients participate. However, as Cornwall suggests, in other institutional invited spaces, this power has been subverted.(35) Maguire and Britten, argue that patient participation happens in 'liminal' space between the personal and social 'lifeworld' spaces that patients inhabit, and the political, economic, and medical-scientific institutional 'system' spaces that professionals inhabit.(94) This 'liminal' space is created at the intersection between 'lifeworld' and 'system' space, and can create unintended opportunities for influence and conflict, where the spaces, and the rules and relationships within them, interact. Other authors have described how patients develop tactics, strategies, and networks within and between spaces to exert agency and power to reshape the participatory space to ensure they achieve their goals, despite the institutional control over the invited space.(45, 57) But little is known about whether PPGs are liminal spaces, the tactics and strategy that patients need to exert to affect change, or how to create the conditions where patients have agency to change the space.

In summary, the evidence base for PPGs is limited with the majority focusing on stakeholders' attitudes and experiences, and self-reported measurable outcomes. Only one study has attempted to directly investigate the impact of PPGs on patient experience, and this showed no effect.(74) Other authors have argued that there is a moral rationale for patient participation, and therefore resources should not be spent on attempting to measure impact or measurement should focus on empowerment as a goal in its own right.(48, 49) This may explain why PPGs have become a mandatory requirement, despite limited evidence of function or effect. Early PPG research raised significant questions about sustainability, despite PPGs being institutional, invited regular spaces. The evidence above suggests this is partly due to role confusion with multiple expectations placed on PPGs, different conceptions of representation, and organisational culture and professional power. No research has been published about PPGs since the contractual changes, despite the potential that these changes have normalised PPGs as tokenistic and subservient. Apart from our pilot study, no research has actually observed what happens in PPGs, the decision making process in action or the dynamics within groups, and whether and how patients can have influence in these institutional spaces. This demonstrates a number of gaps in the literature: what actually happens within PPGs? how can patients meaningfully participate in organisational decision making in general practice? does meaningful patient participation have an impact? and is the impact instrumental or transformative and does this matter?

1.4 Patient participation in improving general practice internationally

Many other countries have pursued attempts to improve general practice through patient participation utilising invited regular participatory spaces similar to PPGs. In North America, PPG equivalents are usually termed patient, community, or patient and family advisory councils or boards.(4) Self-reported patient centred improvements were identified by high function advisory councils in the United States of America (USA).(95) Their high functioning status was due to having a clear purpose, structured diverse recruitment of representatives, and support and facilitation of activities. The implementation of community participation in Irish primary care teams has also been evaluated.(96) Similarly to PPGs, barriers to sustained community participation included organisational factors, and uncertainty about the roles of community stakeholders as representatives, especially from the health care professional perspective. A project to develop a framework for community participation in New Zealand identified varying definitions of participation, with community stakeholders placing the focus on trust building over time rather than consumer feedback.(97)

In addition to invited regular spaces, internationally, general practice has also experimented with fleeting formations: invited transient participatory spaces.(50) One large family practice in USA invited patients to “spend the day with your Family Health Team”.(98) Patients were given training, then observed waiting room interactions, followed by a deliberative discussion between the patients and staff. The authors observed that the participating patients became ‘insiders’, raising issues from their observations, and that the deliberation helped to reframe the doctor-patient relationship. Another USA practice experimented with group concept mapping, inviting both patients and staff to suggest ‘concepts’ for service improvement in the practice before mapping these into clusters.(99) A Canadian study used an action research approach to set up patient councils to brainstorm, then prioritise, then implement service improvements in two family medical centres.(100) All three projects have similarities: they were one off or short term participatory spaces; patients were invited by the organisations for the purpose of service improvement via knowledge transfer; issues of patient representativeness were raised; and a neutral facilitator was an essential feature. Professional power was mentioned in two of the studies, both suggesting that it was essential to have the involvement of doctors in the decision making process.(98, 100) All three were designed as research projects, and only the Canadian study involved patients in the research team.

There has been one randomised controlled trial, and process evaluation, of a systematically designed intervention, aimed at increasing the influence of the public in community health service decision making.(101-103) The intervention involved local multi-stakeholder groups choosing validated quality indicators that they would like to see added to local plans for population health improvement.(101) The trial demonstrated that through a process of consultation (a prioritisation survey) and participation (a facilitated deliberative meeting to discuss priorities), both the publics’ and professionals’ priorities for quality of care changed, building mutual consensus.(101) Overall priorities were more patient centred when patients were involved, and more technical and clinically focused when patients were not involved.(101) However, reaching a decision took more time and cost more money when the public were involved.(101)

The process evaluation identified three theoretical constructs necessary for meaningful public involvement in health service decision making (102):

- The public must have **credible knowledge** to contribute to decision making process.
  The public participated in a knowledge transfer mode of participation as "experience-based experts". Credibility was developed through training, access to validated quality indicators, and population survey data, enabling public participants to interact "meaningfully" with professionals.
- The public members' role as representatives must be **legitimate**.
  Representative legitimacy was attained through: a rigorous recruitment and sampling process; the collection of survey data; and a more subjective process of *'collective speech strategies'* whereby participants actively used others' stories and experiences to demonstrate wider experiential knowledge.
- The public must be able to **influence power**.
  In order to influence power, the public needed voice, mediated by credibility and legitimacy, and opportunity, through deliberation. An expert facilitator was key to ensuring public voice and opportunity within the deliberative process, mitigating the effect of professional power.

There are problems with this model. Although the public participants were described as "experience-based experts", they were required to attend training and learn new knowledge to be seen as competent and credible. This raises issues of epistemic justice: how is different knowledge valued and who decides what knowledge is valued. The intervention strengthened representational legitimacy mainly through mechanisms to establish statistical representation. This raises issues of who judges representational legitimacy, and by what standards. Both these issues demonstrate that the intervention created an emergent invited space, with predefined rules, and an instrumental aim of patient centred community service improvements. It is notable that although public stakeholders were approached to gain support for implementation, no public contributors were involved in designing the intervention, and the lead author is a family physician. Therefore there is a need to test and develop these constructs further, and also take into account the different context of general practice PPGs where patient participation is an ongoing process and resources are limited. Brown concludes that much of the English research on PPGs is dominated by the provider perspective and designed by researchers alone.(25) This can also be said about the international research on patient participation demonstrating a gap in the literature for participatory research involving all stakeholders in the development of patient participation.

1.5 Summary and implications for the intervention design

The current arrangements for patient participation in general practice need to be clarified. It has been suggested that the impact of participation is often not evidenced, because meaningful participation did not occur(23), and opportunities for meaningful participation were not appropriately managed.(42) This undermines the credibility of patient participation and potentially wastes resources (public money, and patient and professional time). Furthermore, opportunities for meaningful participation may be lost. **Therefore, this thesis employed a participatory research approach, working with all stakeholders, to develop and field test an intervention to promote a meaningful approach to support PPGs in general practice organisational decision making.**

‘Meaningful’ participation is often discussed in the literature with few attempting to clarify the terminology.(39) Crompton suggests meaning emerges through *“situated practices of social actors”(p230 (39))* who have different experiences and knowledge of participatory processes.(39) This suggests ‘meaningful’ participation may be defined differently by different stakeholders. This corresponds with patient and staff stakeholders participating in this project who could identify examples of ‘meaningful’ participation, but struggled to define the key elements. Arnstein, Dean, and Cornwall’s typologies of participation help to clarify ‘meaningful’ participation within this thesis.(33, 36, 50) Arnstein suggests for participation to be meaningful it must address power.(36) Dean discusses meaningful participation as the public having influence.(33) Cornwall describes participation as meaningful or not depending on the social interactions between actors within participatory space.(50) This suggests the need to focus on the social interactions of actors, and be clear about the aim and purpose at the outset of any participatory process.(39, 50) Therefore our aim was for Arnstein’s partnership level recognising both patients and staff as equal actors with expertise regarding what is desirable and achievable improvement in general practice.(36) Our rationale was Dean’s solidaristic participation, striving for equitable service improvement for all, not just for those who participate.(33) Our desired purpose was for what Cornwall describes as transformational participation.(35) However, Dean and Cornwall also argue for pragmatic approaches to participation recognising the different participation preferences, and the boundaries of invited spaces.(33, 35) Dean argues it is acceptable to use different rationales for participation to encourage different individuals and groups, and especially the powerful to participate.(56) Cornwall suggests once a participatory space is created it can be transformed and have unintended transformative effects.(35) Therefore, this thesis set out to create a pragmatic participatory space which is acceptable to all stakeholders, but with the conditions to allow opportunities for transformative change. Arnstein, Dean and Cornwall all agree that this type of space will require multiple different mechanisms for participation to encourage a wide and diverse public with different views and preferences for participation.(33, 36, 50, 56) Therefore the intervention combined two participatory mechanisms: *partnership working* between patients and staff in PPGs, and *consultation* with the wider public using a prioritisation survey.

The design of the intervention outline drew on the existing evidence for patient participation in general practice and other public service settings, both in England and internationally, and a preliminary study of patient participation in primary care conducted in 2014 and designed to inform the PhD fellowship funding (see Appendix 1 and Section 2.5.2.4). This evidence suggests the need to be clear about role, critically explore representation, and be transparent about power. To address these issues the intervention drew heavily on Boivin's theoretical constructs:

- A mechanism of partnership working providing PPG members with **credible knowledge** about the wider features and organisational constraints of general practice, and opportunities to use this knowledge to influence service improvement decisions.
- A legitimate method of consulting the wider practice patient population about their priorities, aiming to achieve **statistical representation** through a survey. This aimed to raise wider awareness of the PPG increasing recruitment, and hence **representational legitimacy** of the PPG.
- A safe deliberative space, **ameliorating the effect of power** through the use of participatory methods and facilitation.

This provided an initial structure for the intervention in PPGs in general practice:

- Partnership working in one or two meetings with patients and staff to adapt a pre-designed prioritisation survey;
- Support to conduct a consultation with a representative sample of the patient population through a prioritisation survey;
- A follow up meeting with patients and staff working in partnership to develop an action plan based on the results.

1.6 Aims and objectives

There are two aims of this project: the first is practical and action orientated and the second concerns generating theory about the process of participation.

1.6.1 Practical aim:

To develop and test an intervention to strengthen the role of patient participation in general practice service improvement.

1.6.2 Theory aim:

To explore the space and relationship between patients and general practice staff when they try to work together to share organisational decision making.

1.6.3 Objectives

1. To develop an intervention, working with all stakeholders, to enable patients and staff to work in partnership to set service improvement priorities in general practice.
   Chapters 3 and 4
2. To field test the intervention with two general practice PPGs aiming to generate patient centre service improvements in those practices.
   Chapters 5 and 6
3. To evaluate whether the intervention leads to meaningful patient participation in general practice service improvement.
   Chapters 5 and 6
4. To explore the space and relationship between patients and general practice staff when they work together to improve services.
   Chapter 7

2. Methodology Overview

This chapter provides an overview of the methodology used within this PhD. I will start by outlining the participatory research paradigm that underpins this research and why I chose it. I will then briefly cover some of the different approaches to patient participation research, and intervention design, which influence this PhD. **I will then explain the participatory action research methodology used within this PhD to develop and evaluate an intervention to strengthen patient participation in general practice service improvement.** I will justify the use of normalisation process theory and the prioritisation survey, both developed in other paradigms, but used within this PhD under a paradigm of participatory research. Finally, I will discuss the ethical considerations related to participatory research and this project.

2.1 Paradigm, ontology, and epistemology

A research paradigm is a belief system that grounds a set of practices. A paradigm is characterised by its ontology (definition of reality), epistemology (definition of knowledge), and methodology (systemic approach to discovering knowledge).(104) Defining a paradigm as a belief system, highlights the connection between the researcher and the research. The belief system of a researcher drives the research in terms of their approach to discovering knowledge, their definition of what knowledge is, and how this knowledge affects the reality in which they live. One method of inquiry is not necessarily better than another. The issue is that each paradigm comes with its own set of underlying assumptions and rules.

There are two dominant paradigms in health research: positivism and interpretivist.(104) The positivist paradigm is characterised by a realist ontology and objective epistemology: there is one reality and one objective truth about this reality.(104) Positivists believe that the natural world can be observed and measured through an objective, rational, and neutral experimental approach. Therefore positivist research tends to be quantitative and randomised controlled trials are viewed as the gold standard test.(104, 105) Evidence Based Medicine is rooted in the positivist paradigm.(105, 106)

In contrast, the interpretivist paradigm is characterised by a relativist ontology and subjective epistemology: there are multiple realities which depend on how individuals interpret their own reality.(104) Interpretivists are interested in exploring the world from multiple perspectives and aim to understand how and why different people interpret the world differently. There are a number of interpretivist approaches including social constructionism, phenomenology, and critical approaches. What unites them is their use of qualitative research methods which aim to understand, explore and explain the world using thick description, rather than counting or measuring it.(107) However, some qualitative research has been criticised for observing and interpreting subjects from a distance, and there are increasing ethical concerns about the ownership of the knowledge produced and the benefit to the research subjects.(104)

Participatory research is a relatively newer paradigm that takes an explicitly ethical approach that research should be collaborative, with the 'researcher' and 'subject' having equal ownership of the knowledge created.(24, 104, 108) Jagosh et al define participatory research as:

> *"The co-construction of research between researchers and people affected by the issues under study and/or decision makers who apply the findings of the study"* (p312).(24)

They emphasise equal partnerships between those conducting and those whose lives are directly affected by the research, with all stakeholders involved *with* (not just participating *in*) every aspect of a study.(24) The International Collaboration for Participatory Health Research (ICPHR) describes participatory research as a paradigm because *"participation is the defining principle throughout the research process"* (p4)(108). They distinguish this paradigm as distinctly different to studies that incorporate participatory methods at selected time points in the research (for example utilising participatory approaches to help design recruitment materials or dissemination of results).(108) Participatory research is based on constructivist ontology, in which reality is not concrete but changing depending on time, person, and place, and a subjective epistemology recognising that different people have different ways of understanding and making sense of the world and hence reality.(104, 108) It is based on dialogical processes which illuminate the different realities of all those involved and it is inherently interested in power dynamics in partnerships and the construction of realities.(108-110) Participatory research does not privilege one method over another, therefore studies can be qualitative, quantitative, or mixed methods.(24, 108, 111) This recognises that plurality of methods is an epistemic strength enabling a multi-layered participatory world view. However, participatory researchers also recognise the importance of scientific quality and rigour in the use of methods, and the need to be transparent about how the knowledge has evolved.(19) **This chapter outlines the rationale for bringing together research methods usually associated with contrasting established paradigms, under an overarching participatory paradigm.** Given the interest in power, and the importance of transparency, in the approach and methods, reflexivity is an essential feature of participatory research. In the next section, I cover reflexivity in relation to my personal beliefs, role as a GP, and the relevance of participatory research for researching patient participation in PPGs.

2.1.1 Reflexivity

Reflexivity has multiple meanings and interpretations.(108, 112) The ICPHR use the term critical reflexivity to draw attention to power differentials in the process of research and how and by whom knowledge is generated and used.(108) They distinguish critical reflexivity as an essential process of raising what Freire discusses as critical consciousness in the pursuit of emancipation.(109) This is distinct from technical and practical reflexivity when health care professionals reflect on the quality of their practice, and training or professional guidelines.(113) Three concepts of reflexivity have been identified depending on the content, focus, and consequences of the reflexivity:(112)

- Citizen self-actualisation leading to individual emancipation;
- Practitioner awareness of the subjectivity of knowledge and reflection-in-action resulting in the emancipation of the disempowered;
- Practitioner awareness of their role, context, emotion, cognition, and power and the effect on the disempowered.

If reality is subjective, critical reflexivity about the identity and process of generating knowledge about reality is essential.(114) **My personal ontological and epistemological perspective is that reality is socially constructed and knowledge of this reality differs depending on an individuals' experience of this reality.(104) This aligns with a participatory research paradigm.** Investigating reality from multiple perspectives allows a wider, more comprehensive, knowledge of a particular reality.(113, 115) Observing behaviours and actions of different individuals and groups involved in a particular reality, can provide the observer with an understanding of how different individuals and groups know this reality.(104) However, involving people with lived experience of this reality, in reflexively exploring and understanding their own, and others' experiences of a reality, produces an in-depth multi-perspective knowledge.(113) In addition, collaborative creation of knowledge can be empowering and disruptive of traditional knowledge hierarchies where the observer retains, and does not always share, their knowledge with those living in the reality being studied.(109) **Co-creation of knowledge can be transformative; as those directly involved, retain the knowledge and can act on, and potentially change their own reality.(24, 109) Therefore, it is appropriate for my PhD to use a participatory research paradigm as this matches my personal belief system.**

It is also important to be reflexive about the context of this research, and my background as a general practitioner (GP). The research is funded by the National Institute for Health Research (NIHR), I work within a university medical school, and my GP training was strongly influenced by Evidence Based Medicine. The dominant paradigm within these institutions is positivism. Evidence Based Medicine has been criticised for being biased against the contribution of patient and carer knowledge, resulting in epistemic injustice.(87, 116) Epistemic injustice is heavily influenced by the culture of medical paternalism which still exists and can be described as a form of oppression.(87, 109, 116, 117) Therefore, within this PhD, patients are conceptualised as being disempowered compared to GPs. Consequently it is essential that I am reflexive about my background as a GP, and how this influences this research. For example I am aware that many service improvements are initiated to improve GP workload (93), that doctors often do not value the same service features as patients (118, 119), and that patients are often disempowered in their ability to influence service improvement.(120)

Participatory research is ideal for investigating patient participation in general practice service improvement, as it enables the exploration and knowledge sharing of different stakeholders' reality of collaborative working. Patients, clinicians, and managers sharing their experience of working within PPGs, may facilitate shared understanding of this partnership working, and help to overcome barriers that could not be addressed by one stakeholder group working alone. Non participatory research about PPGs demonstrated organisational barriers to effective partnership working, that some patients recognise, but have little agency to effect.(67) This research did not change this situation. Participatory research aims to bring stakeholders together to effect change.(24, 108) For example, participatory research with migrants in general practice, demonstrated that by migrants, general practice staff, and researchers working together, even a marginalised group such as migrants, were able to influence organisational change.(121, 122) This work identified that different stakeholders had different knowledge about the feasibility of adapting and implementing guidelines to their local context.(121) Working together was enjoyable, and trusting relationships developed which resulted in the sharing of implementation work and sustained implementation over a four year period.(121, 123) More detail about the resonance of the participatory paradigm are in Sections 2.3 and 2.5. Next, I will briefly discuss how approaches to patient participation in research have evolved over the last twenty years.

2.3 Approaches to patient participation in research

There are a plethora of terms for patient participation in healthcare and research, with multiple philosophical rationales and underlying values (see Chapter 1).(33, 35, 36, 50, 124) Many approaches to patient participation in research, are associated with an instrumental quality and efficiency rationale and substantive values: by involving patients the research will be better or more likely to have impact.(48, 124, 125) This approach is consistent with Dean's participatory mode of knowledge transfer: the public are experts by experience and are included in decision making in the research process as other experts and valued for their knowledge.(33) This often frames patient participation in intervention design and implementation as a mechanism to reduce the knowledge translation gap.(125, 126) This led to a focus on measuring the impact of patient participation on research outcomes.(3, 12, 127) The lack of measurable impact led some to suggest participation was tokenistic, and others to suggest meaningful participation did not occur.(23) This shifted the focus to the *process* of participation, to try and unpack what was going on and to understand the complexity of factors that influence outcomes.

This resulted in increasing interest in partnership processes between researchers and patient and public contributors, such as co-production and co-design, in both research and service development.(124, 128) However, it could be argued that the underlying philosophy is still instrumental knowledge transfer. Experience based co-design, which was initially developed as a participatory research project, has been converted into a step-wise off-the-shelf method of service improvement which is also used in intervention design.(129, 130) Cornwall would describe these participatory spaces as “fleeting formations” with research institutions working in collaboration with healthcare institutions to provide short term spaces aimed at improving the quality of interventions in a pipeline approach to improving the quality of care.(50) Some of these spaces have resulted in transformations such as the empowerment of patient partners and patient centred service improvements, but there is little long term follow up.(59, 131) One long term follow up study found some participants describing the process as emotionally manipulative and others objectifying the physical project outputs, rather than service transformation, as evidence of success.(132) There are now increasing calls for a transformative rationale for PPI in research, which means a renewed focus on the normative values about the public’s rights to participate, power in the participatory process, and the transformative empowering potential of participation.(48, 124, 133)

Participatory research aligns with Dean’s collective decision making mode of participation: equal power for all in every decision making process and aims for transformative participatory spaces.(33, 35) Participatory research aims for equal partnerships between those conducting and those affected by the research, with all stakeholders involved *with* (not just participating *in*) every aspect of a study, recognising participation as a right and the value of different forms of knowledge including experiential knowledge.(24) Participatory research such as this has both instrumental and transformative outcomes including:

- Culturally and logistically appropriate research

- Increased recruitment
- Capacity development for all stakeholders
- Productive conflicts between stakeholders which disrupt power relations and result in negotiation of useful resolutions
- Increased quality of outputs and outcomes over time
- Sustainability of interventions with less reliance on external funding
- System transformation and spin off projects

As indicated by my aims and objectives (Chapter 1) system transformation and sustainability were significant aims of this PhD. These outcomes are achieved in participatory research through partnership synergy which develops over time and results in increasing trust between partners.(24, 134) Increased trust reinforces partnership working, maintaining and sustaining the relationship and allowing space for spin off projects and unanticipated system transformation. This has been termed the ripple effect.(134) Ripple effects may include increased confidence and empowerment of individual research partners, especially community partners, or new research or policy collaborations.(123) However, partnership synergy takes time to develop, often years.(24, 134) This is not always supported in current research institutions and culture. Some participatory research projects do not result in completely positive outcomes.(24) Unresolved conflict has resulted in partnership breakdown and a loss of trust.(24) Structural and institutional barriers have prevented sustainable implementation.(123) Historically participatory research was criticised as only generating locally relevant knowledge that was not transferable.(135) However, with the increasing use of theory (see section 2.6) and the importance of the role of complex adaptive systems, participatory research is seen as a more ethical and flexible research paradigm.(105, 106, 136)

2.4 Intervention design

Over the last 30 years, there have been concerted efforts to improve healthcare through Evidence Based Medicine.(105, 106) This has created a science related to the design, development, evaluation and implementation of complex interventions. Complex interventions involve multiple interacting components, processes, and stakeholders with different realities and world views.(18) The most prominent contribution to the field has been the Medical Research Council (MRC) guidance on the design and evaluation of complex interventions. (18, 137). The original framework depicted a linear approach, emphasising 4 stages(137):

- Intervention development based on existing evidence and theory,
- Preliminary testing to understand the components of the intervention and feasibility,

- Evaluation,
- Effective implementation.

The framework was revised in 2006 with a greater focus on intervention development, iterative processes, flexibility and tailoring of interventions to local context, and earlier focus on implementation issues.(18) However, critics have continued to call the MRC guidance a pipeline approach with too much emphasis on the positivist measurement of interventions in randomised control trials with binary outcomes that the intervention works or fails.(105, 106)

As a result there is growing interest in intervention development and implementation, specifically *how to develop interventions* and *how to implement sustainable interventions at scale.* A recent review described eight different broad approaches to intervention development and another review identified 61 different theories, models and frameworks of implementation.(138, 139) There is now non-prescriptive guidance on how to develop complex interventions flexibly.(126) However, there is a lack of good quality evidence regarding the utility of this guidance. Implementation research has also evolved and increasingly recognises the value of interpretivist approaches, and the effect of context, specifically complex adaptive systems, into which complex interventions are implemented.(105, 106, 140, 141) However, intervention development and implementation are still often reported separately and proceed in step-wise sequence maintaining the pipeline approach. This is exemplified by Hoddinott's definition of an intervention development study:

> *"A study that describes the rationale, decision making processes, methods and findings which occur between the idea or inception of an intervention until it is ready for formal feasibility, pilot or efficacy testing prior to a full trial or evaluation."(142)*

This technocratic definition of intervention development is grounded in the positivist paradigm, and based on the epistemology perspective that an intervention is a discrete object which can be defined, described, and tested. This is contrary to the paradigm of participatory action research and Burns' definition of interventions as:

> *"Interruptions to disabling or disempowering systemic patterns"*(p9).(143)

The Burns definition focuses on the outcome, "interruption", as the defining part of the intervention. The focus is on what the intervention does, rather than generating a discrete intervention which can be replicated with the same expected results.(143) **This is why I define patient participation in general practice service improvement as an intervention.** As per my aims and objectives, I am interested in the transformative potential of patient participation to disrupt systemic clinician led approaches to general practice service improvement.

General practice is a complex adaptive system, undergoing significant and potentially ongoing change.(144) Complex adaptive systems respond to change in often unpredictable ways which are not linear or proportional to the inputs and can appear random and unexplainable.(140, 141) Burns suggests an intervention can only be defined as such if it has an effect on the system: it is transformative.(143) This is an argument for taking a flexible approach to intervention development, where the focus is grounded in the complex adaptive system and the stakeholders that work within that system, allowing constant iteration with the implementation of the intervention. The focus should be on ongoing iterative cycles of intervention design and implementation with concurrent experiential learning. **Evaluation is a key process of learning, rather than an endpoint. This is the approach that I have taken during this PhD.** However, this approach to iterative working requires a robust methodology which can capture the learning and harness this knowledge to affect change. This methodology is participatory action research and will be discussed next.

2.5 Participatory Action Research Methodology

The participatory research paradigm has its origins in development studies and the global south.(2) It is an umbrella term for multiple approaches: participatory research, participatory health research, community based participatory research, and participatory action research to name a few.(108, 145) I use the term Participatory Action Research (PAR) to describe this research as the inclusion of 'action' emphasises the aim to bring about change. This has its roots in Paolo Freire's Pedagogy of the Oppressed.(109, 110) Freire argued that critical reflexivity is essential for raising consciousness.(109) In PAR critical reflexivity is stimulated through dialogue, sharing perspectives, and reflecting on different perspectives. This process is implicitly described in action research cycles (Figure 2.1) which create space for dialogue and reflection in, and on, action. This is a process of discovery, learning, and problem solving.(146)

Figure 2.1. Action research cycle

As participation throughout the research process is the defining principle of PAR, I worked collaboratively with patients and general practice staff throughout the project. This involved sharing decision making and ownership of the project design, governance, data, and resulting knowledge.(19) To achieve this, I established a multi-stakeholder co-operative inquiry group called the co-research group (CRG).

2.5.1 Co-operative inquiry

Co-operative inquiry (CI) is an established PAR method, in which groups move through cycles of action and reflection.(113, 115, 147) CI groups are multi-stakeholder groups established due to a shared aim to change their social situation whilst also generating theory about that change.(110, 114, 135) As mentioned above, in this project CI happened within the multi-stakeholder CRG throughout the project. CI discussions aim to generate emergent knowledge by bringing together different perspectives, or ways of knowing the world, through discussion. Heron and Reason describe four ways of knowing in relation to PAR (147):

1. Experiential knowing – face-to face experience of people, objects and events. This is tacit knowledge that everyone has and is unique to all individuals based on their experience.
2. Presentational knowing – how to describe an experience, often using a physical creative form, in this project most closely aligned with being able to express a story of experiential knowing in a form that will be listened to.
3. Propositional knowing – the ideas and theories about how the world works, resulting in the ability to make generalisations or to be able to transfer knowledge from one setting to another.
4. Practical knowing – this underpins the skills and confidence of how to do something.

Heron and Reason describe how CI enables critical investigation of all four ways of knowing together.(147) This is essential, as if one way of knowing is privileged it may result in theories that are not based on experience, or action and experience that cannot be explained or shared.(113, 115, 146) CI groups aim to generate change and knowledge by working through action research cycles of problem identification (generating propositional knowledge), planning (generating practical knowledge), action (generating experiential knowledge), and evaluation (generating presentational knowledge) (Figure 2.1).(115)

The validity of the CI lies in three processes.

- CRG members are encouraged to participate in all aspects of the research.(113, 115) Participation in *doing* the research means CRG members are able to explore the topic through all four ways of knowing it.(147) In CI partners are encouraged to theorise, try out new skills, and explore new experiences. This compares to participants in a focus group, where the sole focus is on presenting existing experiences for a researcher to extract.
- Secondly, the CRG space actively encourages challenge and alternative views, aiming to seek disconfirming data.(113) Inviting constructive challenge relies on skilful facilitation.
- Thirdly, diversity of experience is essential to ensuring multiple ways of knowing are brought together, strengthening collective emergent knowledge. Equity of voice is essential to ensure that all ways of knowing are given equal weight, and there is space for critical reflection on difference.(113) Equity of voice can be encouraged through the use of participatory methods (Table 2.2).

The CRG brought together all stakeholders and encouraged them to participate in all aspects of the project. The CRG was an invited regular participatory space attached to an institution (the university). However, challenge and reflection on this challenge were encouraged throughout our work.(50) I will now outline the CRG in more detail.

2.5.2 The co-research group

The CRG is a multi-stakeholder group of people with different knowledge about PPGs. The aim was to include all stakeholders of PPGs (patients, clinicians, administrative staff, and local commissioners) reflecting the diverse range of experiences of PPGs and invested interests.

2.5.2.1 Co-research group recruitment and retention

Recruitment to the CRG was through local networks of known individuals and opportunistic invitation to key stakeholders, some of whom had been involved in the prior related 2014 research project (see Appendix 1 and 5). Over the course of this project the following stakeholders were involved in the CRG:

- Eleven members of the public with different experiences of PPGs,
- Six GPs, some with other external roles including clinical commissioning roles,
- Two people employed by local involvement charities (both charities were approached as they had a remit around involvement, inclusion, and diversity),
- One clinical commissioning group engagement lead (employee responsible for ensuring patient involvement and engagement in organisational decision making, within all local NHS organisations),

- One receptionist and practice engagement lead,
- Myself

Despite considerable effort we were unable to recruit Practice Managers or other practice staff (including nurses who rarely take part in PPGs) to the CRG (see Appendix 5). Table 2.1 shows detailed characteristics of the co-researchers. Some demographic details (individual socioeconomic status, the age of staff, the name of individuals' general practice where they are a patient) were not collected as they were not deemed essential for the research. Some details have been omitted or left vague (primary role and ethnicity) in order to protect anonymity. Where co-researchers were a member of staff or an active PPG member of a general practice, demographics of the general practice population have been included as a proxy for individual demographic characteristics.

Table 2.1. Characteristics of the co-researchers

Initials	Primary role	Gender	Age	Ethnicity	Practice ethnicity*	Practice IMD*^
MR	PPG member	M	63	White	47.9% w	32.4
MK	PPG member	M	76	White	81.4% w	18.3
RC	Virtual/failed PPG member	F	57	White	86.9% w	45.9
DM	Involvement charity	F	53	Black	-	-
NB	PPG member	M	49	White	85.3% w	44.1
AD	PPI in research	F	68	White	-	-
VBB	CCG Engagement Lead	F	Not asked	White	-	-
SP	Salaried GP	F	Not asked	White	47.9% w	32.4
TF	GP Partner	M	Not asked	White	85.3% w	44.1
RM	Ex-PPG member	F	52	Asian	-	-
GP	CCG Lay member	M	63	White	-	-
RA	PPG member	M	62	White	67.4% w	27.8
BD	PPG member	M	78	White	-	-
MJ	PPG member	M	78	White	-	-
PG	PPG member	M	Not asked	White	-	-
JP	Involvement charity	M	Not asked	Asian	-	-
GS	GP Partner and CCG role	M	Not asked	White	85.7% w	16
ZN	Locum GP & multiple roles	F	Not asked	White	-	-
SL	Practice engagement lead	F	Not asked	Asian	51.3% w	31.3
NH	GP Partner and CCG role	M	Not asked	White	75.4% w	32
AH	GP Partner & multiple roles	M	Not asked	Asian	89.7% w	32.7

**Data from Public Health England: National General Practice Profiles [accessed 5th March 2020].(148)*

^IMD = Index of Multiple Deprivation (Official English government measure of deprivation of small local areas based on income, employment, health, education, housing, crime, and environment indices). Higher number indicates greater deprivation.(149)

A number of people withdrew from the CRG in the first three years. Their reasons included the project not meeting their expectations, the slow pace of progress, and changes in their workload outside the project. However, at the end of the six years a core group remained including seven patient members, one GP, and myself. More details about CRG recruitment and retention can be found in Appendix 5-7. I viewed myself as a member of the CRG. Therefore, in this thesis, when I describe collective work or decision making I use “we”. When I worked alone or made decisions alone, I use “I”.

In CI groups, all members are both participants (subjects) and researchers (observers) aiming for collective self-reflexivity. Collective dialogue produces data and is a process of interpreting data. Therefore data was generated from CRG meetings, which were audio recorded and selectively transcribed, and written reflections on interactions with each other between meetings. All co-researchers were aware of this, and informed consent was obtained (Appendix 3 and 4) after our third meeting or when new members joined.

2.5.2.2 Co-research group methods

The aim of the CRG was for co-ownership of the project, data, and resulting knowledge, and a key feature was joint decision making throughout the study.(19) To reflect this we collaboratively developed a partnership agreement (Appendix 8) and the group took on specific roles such as co-chair and ‘rapporteur’. The group took part in CI discussion meetings throughout the project, sometimes with everyone, sometimes with a smaller group focused on a particular task (task and finish groups). Initially meetings were approximately every four months, however, these increased to monthly or two monthly during the field testing to help with momentum. Meetings were between one and four hours in length. There were 28 full meetings with additional smaller meetings. Co-researchers were offered payment for their time (the same rate for all stakeholders) and expenses.

Most meetings were structured utilising specific participatory methods adapted from those used in Participatory Learning and Action (PLA) (Table 2.2).(150, 151) PLA is a form of PAR with origins in development studies and emerging from tools and techniques used with poor rural communities to generate collective knowledge to aid their empowerment.(152) More recently PLA tools have been used in a number of primary care projects, bringing together both patients and staff, and aiming for equity of voice and knowledge sharing.(121, 153-156) PLA methods were used in the CRG meetings to help structure meetings, and to test these methods through reflection in action, for suitability to use in the intervention with PPGs.

Table 2.2. Participatory methods

Participatory method	Aim of the method
Creative warm up exercises	To enable introductions, set the tone for meetings, and create a safe space for discussion.
Flexible brain storming or thought shower	To generate and exchange knowledge interactively. Participants generated information and ideas on sticky notes which could be viewed by all participants and then be used in other tools.
Card sort	To organise information into categories. Information on cards or sticky notes can be organised in categories to manage the data, make decisions about feasibility, or generate themes.
Charting	To create a visual display of different stakeholders' ideas, thoughts or feelings on a topic to enhance knowledge exchange.
Matrix	To create consensus about the criteria with which to judge a topic. The criteria can then be used to score the topic.
Ranking, scoring and voting	To democratically and transparently agree on priorities. All participants have the same weight of vote. Voting is done together and participants are encouraged to explain their choices.
Speed evaluation	To obtain rapid immediate feedback on the meeting.

Description of tools in this table was informed by (121, 150, 151)

2.5.2.3 Co-research group knowledge generation

The CRG meetings brought together all four ways of knowing about PPGs from multiple perspectives. Meeting as a group and doing the research generated data based on experiential and practical knowing of how to work together. Reflecting on this generated presentational and propositional knowing, grounded in this data. We used this emergent knowledge to develop the intervention and to critically reflect when evaluating the intervention. I kept a reflexive diary and made notes during and after meetings and key events. This was supplemented by reflexive discussions with my supervisory team. The CRG members were also asked to reflect on the process during meetings and individually after meetings using a semi-structured co-designed reflection form, but this was never used. Instead the CRG agreed to a dedicated meeting once a year to reflect on our work and generate group understanding.

2.5.2.4 Co-research group roles in the programme of work

The key principle of PAR is participation throughout the research process. Salsberg et al suggest the most vital times for participation in the research process are developing the research question or agenda, interpreting the results, and agreeing dissemination messages.(19) Participation in developing the research question or agenda is often limited by institutional processes requiring researchers to apply for funding prior to agreeing participatory processes. In this project, as mentioned earlier, many of those who joined the CRG participated in a previous related research study exploring the role of PPI in primary care service delivery directly prior to this project in 2014 (see Appendix 1). This 2014 study directly influenced the design of the intervention outline and the agenda and structure of this PhD (section 1.5). The intervention outline and PhD agenda and structure developed iteratively through group and individual discussions with both patient and staff participants involved in the 2014 research. The 2014 participants requested that this PhD should address patient participation in service improvement, issues of representation through the incorporation of a wider consultation element, and address power by focusing on the development of staff skills as well as patient skills. The idea of a prioritisation survey, including trade-offs, as a consultation method was discussed at the end of the 2014 study and there was interest from patients, and especially staff, for this approach. Staff felt it would help patients to understand how decision making was constrained by limited resources. Patients felt it would help them understand more about how general practice is organised and how different features interact. Therefore, the agenda for this research was informed by patients and staff. However, the CRG was only formed in 2015 after funding was obtained, and consisted of different individuals, some who had been involved in these initial 2014 discussions and some who had not.

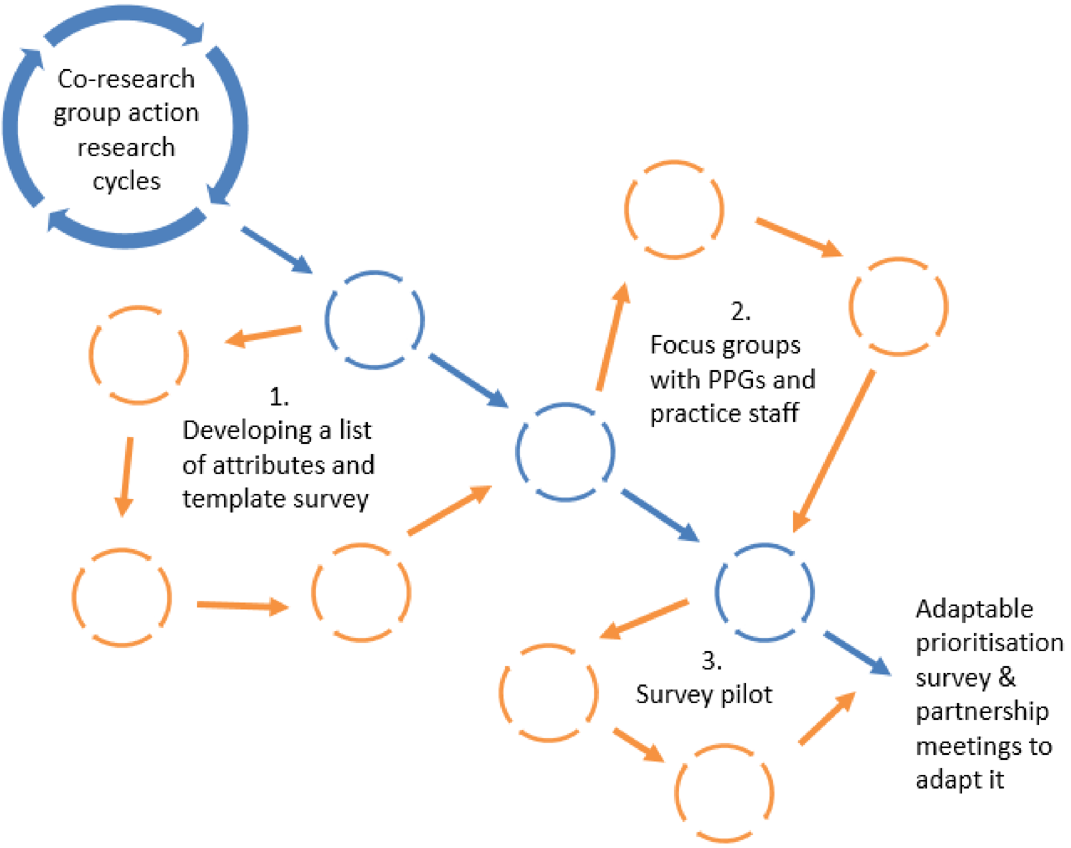
This project involved two phases of research conducted with the CRG. **The first phase involved developing the detail of an intervention to strengthen meaningful patient participation in general practice service improvement (Chapters 3 and 4). The second phase involved field testing the intervention with two general practice PPGs (Chapters 5-7).**

In the first phase (Figure 2.2) the CRG systematically developed, in parallel, the two participatory mechanisms within the intervention: *partnership working*, and *consultation*. Developing the *consultation* participatory mechanism (a prioritisation survey – see Section 2.7 and Chapter 4) involved three sub-phases of work (orange cycles in Figure 2.2):

1. CRG meetings to develop a list of attributes and template survey.
2. Focus groups with PPGs and practice staff to obtain feedback on the attributes, the template survey, and the format and content of partnership meetings to adapt the survey for use in an individual general practice.
3. Survey pilot, including ‘think aloud’ interviews, with members of the public to test the prototype survey.

Throughout these three sub-phases of work, the CRG reflected on and challenged our experiences of working together as a multi-stakeholder group (See Chapter 3). The knowledge this generated was utilised to develop the detail of a series of intervention meetings which comprised the *partnership working* participatory mechanism of the intervention (blue cycles in Figure 2.2).

Figure 2.2. Overview of the co-research group work developing the intervention.



Key:
Blue cycles – CRG work developing *partnership working* participatory mechanism
Orange cycles – CRG work developing *consultation* participatory mechanism

In the second phase of the project the CRG field tested the intervention with two PPGs. We structured this phase to share learning of implementing the intervention horizontally between the PPGs, and vertically with the CRG (see Figure 2.3 and Chapters 5-7). This is a systemic action research approach that has been advocated to share learning from individual CI groups, resulting in emergent knowledge about systemic and structural barriers to action.(143, 157) This is in response to criticism that knowledge generated through PAR is not transferable, and action tends to be local rather than systemic.(157) This will be discussed in more detail in chapter 5. A complementary approach to increasing the transferability of knowledge generated through PAR is to focus on the use and development of theory which will be discussed next.

Figure 2.3. Overview of the co-research group work field testing the intervention.

Key:
Blue cycles – CRG work evaluating the intervention
Orange cycles – PPG work implementing the intervention

2.6 Theoretical approach

PAR explicitly aims to generate theoretical knowledge whilst bringing about social change.(135) The validity of PAR lies in recognising and integrating different forms of knowledge, including propositional knowledge or theory.(115) Theory can emerge from a PAR project inductively, or existing theory can be utilised at a local level deductively to recognise barriers and solutions in the pursuit of change. Theory has been defined as analytical constructs, statements, or propositions which attempt to understand and explain the world.(139, 158) Theories attempt to explain why specific relationships lead to certain events or actions, and therefore can be predictive.(158) Depending on their level of abstraction, theories can be transferable and broadly applicable.(139, 158) Therefore, theory enables the knowledge produced from a PAR project, whether inductively or deductively derived, to be used in different settings and contexts. In this project we aimed to use theory deductively in both the intervention development and evaluation, whilst also being open to the potential to modify existing theory, or develop new theory.

It is now accepted practice to use theory in designing, evaluating, implementing and disseminating complex interventions.(18, 139) Theory can also be used to design (prospective use) or evaluate (retrospective use) intervention development and implementation research.(139) Theory is important in understanding the translational gap between an intervention working in theory and how and why it works in practice.(158) However, complex interventions are still seen as being under theorised both when they are designed and implemented.(159, 160) This is despite 61 different theories, models and frameworks being used in the implementation and dissemination of complex interventions.(139) Citation mapping of these theories suggests there appears to be theory saturation, with only a minority of theories being repeatedly used.(139, 161) Therefore, using existing theory deductively is a strength as it reduces research waste by avoiding duplication, increases the likelihood of implementation success, and contributes to the evidence base and refinement of the existing theory.(139)

Given the existence of multiple theories of implementation, there needs to be a clear rationale for choosing which theory or theories to use.(139, 158) As there are considerable overlaps between theories, models and frameworks, it is recommended to review the goal, setting, population, and context in which a theory was developed and match this to your research context.(139) To aid this theories have been categorised by the construct flexibility (operationally broad to narrow), the focus (dissemination or implementation), and the socioecological dimensions of the theory (individual, organisational, community, system, policy).(139) Alternatively theories have been classified based on their purpose: process or action models (how to implement research); deterministic frameworks and theories; and evaluation frameworks.(158) Deterministic frameworks and theories can be further divided into frameworks which describe implementation barriers and enablers, and theories which explain mechanisms of change. These theories may be specific to implementation, or classic theories from psychology, sociology, or organisational research, or other disciplines.(158)

As discussed in Chapter 1 there is a significant evidence gap regarding how to make patient participation in general practice routine and sustainable. This is an implementation problem that needs to be explored and understood, before addressing scalability and diffusion. This suggests the need for a specific broad implementation theory, rather than a dissemination or classic theory, and a theory which is deterministic and explanatory rather than a process or evaluation model. Therefore, theories which focus on dissemination such as Diffusion of Innovation can be discounted.(139, 162) Equally, frameworks which highlight barriers and enablers to implementation, but that do not explain change, for example Theoretical Domains Framework, can be discounted.(158, 163) Finally, it is important to match theory to the appropriate to the socioecological context. Patient participation involves complex relationships and organisational culture.(67) This suggests the need for a theory which goes beyond individual behaviour, discounting behaviour change implementation theories such as COM-B (Capability, Opportunity, Motivation and Behaviour).(158, 164) Normalisation Process Theory (NPT) is a mid-level implementation theory which describes the collective work stakeholders need to enact to implement interventions in the real world.(165-168) It has been categorised as fairly operationally flexible, and covering individual to system level implementation factors.(139, 158) Next I will outline the theory and the advantages of using it in this project.

NPT outlines four component mechanisms that actors need to adopt to embed a new practice.(168) These four mechanisms are coherence, cognitive participation, collective action, and reflexive monitoring (Table 2.3). These mechanisms are linked and interact: actors commit to practices that have meaning, they put effort into practices that they commit to, their appraisal of practices is related to the effort required to enact a practice, and appraisal generates meaning about a practice. All four components are necessary for practices to become routinized and embedded. The work is not linear and in complex social processes actors are constantly and iteratively working on all four mechanisms. NPT does not explicitly address power, however, it is implicit that actors must have agency to do the work to enact a practice. Therefore factors which limit agency, or coerce or obligate individuals into collective action may be identified by NPT as factors which inhibit the work of embedding an intervention.

More recently, but after this study began, NPT has been extended to understand the relationship between collective action and context within complex adaptive systems.(169) Interventions are described as plastic (they can mould to a context) and contexts as elastic (they change shape to allow interventions space). Implementation is framed as the collective action of participants adapting interventions and shaping contexts to find a new equilibrium.(169) Therefore, interventions which are plastic and can be moulded to a context, and contexts which are elastic to allow interventions space, are more likely to be successful. Extended NPT (ENPT) aims to understand the contribution of the intervention and context to the implementation success or failure, and why some interventions are successful in one context and not in another.(169) Therefore ENPT is most useful once an intervention has been designed and is being implemented in a number of different contexts. The focus of this thesis was on developing and testing the intervention before implementing the intervention more widely. Therefore we used NPT, focusing on understanding the collective action of the intervention, rather than ENPT. NPT has the added benefit of having fewer component mechanisms potentially making it easier to use for multi-stakeholder co-researchers. However, being aware of relationship between the intervention and the context is, of course important at the design phase. Cognisant of ENPT and issues of context, a key focus for our design was that the intervention should be flexible and adaptable, emphasising plastic properties. In addition, the NPT component mechanism collective action includes exploring contextual integration. Attention to this mechanism was important to help highlight elastic contextual factors which can be explored in greater detail using ENPT in future work when implementing the intervention more widely.

Table 2.3. NPT constructs (167)

Construct	Construct summary
Coherence	How stakeholders make sense of the intervention. This involves the stakeholders understanding: - how the intervention is different from their usual ways of working (differentiation), - their individual understanding of the intervention (individual specification), - their collective understanding of the intervention (communal specification), - whether and how they value the intervention (internalisation).
Cognitive Participation	How stakeholders get others engaged and involved in the intervention. This involves stakeholders: - being the right people to be involved (enrolment), - being willing and able to engage others (initiation), - being able to identify the tasks and activities required to sustain the intervention (activation), - believing it is appropriate for them to be involved (legitimation).
Collective Action	The work that needs to be done to deliver the intervention or desired outcome. This involves: - recognising what work needs to be done and the potential burdens of this work (interactional workability), - recognising the skills needed for the work (skill set workability), - confidence that the work done will produce the desired effect (relational integration), - ensuring local and national resources and policies support the work (contextual integration).
Reflexive Monitoring	Reflexive monitoring describes how stakeholders monitor and evaluate the intervention. This includes whether stakeholders will be able to: - judge the effectiveness of their work (systematisation), - judge it individually (individual appraisal), - judge it collectively (communal appraisal), - modify the new way of working based on their experiences (reconfiguration).

NPT is appropriate for this project for a number of reasons. NPT focuses on the work that stakeholders do collectively and has been described as a theory of action.(167) Therefore NPT is appropriate within a PAR paradigm where the focus is on understanding the process of achieving collective action. Importantly, NPT has been used across the design, evaluation, and implementation of interventions.(165, 166, 170) and with multiple stakeholders.(170) Early work focused on professionals and policy makers, but increasingly NPT has been use to explore the work of patients managing their own health.(165, 170, 171) NPT has been used extensively in primary care settings to aid intervention design, analysis, and implementation planning.(172) NPT has been used to evaluate the normalisation of PPI in other settings, particularly research.(23, 173, 174) Finally, NPT has been used in combination with other theories which has been described as a strength, as one theory is unlikely to be perfect.(158, 170) This includes NPT being used with Participatory Learning and Action to prospectively shape interventions specifically to surface and address issues of power,(156, 175) and PAR to evaluate the normalisation of PPI in a research setting.(174) The action orientated participatory methods promote enactment of the NPT constructs and address power.(175) It is therefore a credible and flexible theoretical framework for understanding and describing the important features of our intervention to strengthen PPGs and can be used in developing and evaluating the intervention.

2.7 Prioritisation survey

Arnstein, Dean, and Cornwall all agree that using more than one method of participation is a strength as it recognises heterogeneous public preferences for participation.(28, 33, 35, 36, 50) Within this PhD one element of the intervention is a Discrete Choice Experiment (DCE). A DCE is a survey method grounded in economic theory and used to investigate individual and population preferences.(176) Arnstein would term surveys as a consultation form of participation.(36) Plurality of methods is a strength in PAR, however PAR also emphasises the importance of being transparent about the rationale for using different methods and the validity of the methods.(19, 24, 108) The rationale for using a prioritisation survey within a PAR study will be discussed below, the validity and rationale for using a DCE over other prioritisation methods will be discussed in Chapter 4.

Health policy currently promotes the marketization of healthcare as a means to achieve efficiency.(33, 38, 177) Efficiency describes the distribution of resources to different types of healthcare which produces the maximum health benefit.(177, 178) This rationale is underpinned by economic theory that resources are finite, and there are potentially infinite demands for health and ways of using available resources to achieve health.(178) Therefore, achieving efficiency involves difficult decisions about how to use resources. Choosing to resource one type of healthcare, means that other types of healthcare will not be resourced, resulting in opportunity costs.(177, 178) Health economics is the science of marginal analysis, or measuring and understanding the effect on overall health given small differences in combinations of resource allocation, and how decisions about resource allocation are made.(178)

In England, GPs are independent providers, who have some budgetary control and the ability to make decisions about how healthcare resources are used within their general practice.(92, 93, 179) The characteristics of primary care include providing the first point of access, continuity, co-ordinated, comprehensive, person-centred, family and community orientated care.(180) General practice services include key attributes such as being able to see a preferred doctor, being treated as an individual, and clinical competence.(181) These characteristics and attributes are multi-factorial and interrelated. In a resource limited setting, prioritising improvement of one characteristic (e.g. access) affects other characteristics (e.g. continuity). General practices are responsible for making decisions about where they prioritise their resources and the opportunity costs of resourcing one attribute over another. This can be framed positively in terms of allowing general practices to be flexible to local needs, and negatively in terms of variation in practice.(144)

There are arguments about the role of GPs as decision makers within health economics.(177) On the one hand, GPs are framed as an agent of the patient, with the patient assumed to have inadequate health knowledge to make informed decisions. An agent is someone who acts on behalf of another person. The perfect agent has the same utility, rationality, and self-interest of the person they represent, and therefore will perfectly represent their values and judgements. If this perfect agent relationship existed, GPs would make the same decisions as patients would if they had the same health information. There are considerable problems with this framing.(177) GPs are expected to be agents for both individual patients and populations of patients, at times these can be in conflict. Utility is influenced by a range of sociocultural factors and it is very rare to find any two people whose utility align exactly. Lipsky’s framing of GPs as street level bureaucrats aiming to maximise their own resources, suggests that it is unlikely that patients and GPs utility aligns.(92, 93) This is repeatedly demonstrated in research comparing preferences of patients and doctors.(101, 118, 119) Doctors, including GPs, assume outcomes of care (better health) are more important than the process of care (dignity and autonomy), when the reverse is often true for patients.(101, 118, 119) This is a strong argument for involving patients directly in making decisions about how resources are used within general practices.

In a market system, one mode of patient participation is choice or exit, and voice.(33, 182) A feature of a competitive market, is that if the quality of a service reduces, consumers have two approaches to improving the quality of the service: exit and voice.(182) Exit describes the capacity of an individual consumer to leave a service that no longer meets their expectations, and choose a different service. This assumes that there are many service providers, there is free entry and exit, and the buyer (patient) has full information about the quality of different services. The alternative approach, voice, describes an individual staying with the service, but actively using their voice to improve quality. This relies on the individual believing that their voice will be listened to and acted on. Exit and voice are interdependent: the more real the threat of exit, the more effective voice becomes. Arguably since the early 2000s the health policy rationale for promoting patient participation has been to make voice more effective, whilst also publishing data, including patient satisfaction data, to promote realistic choices and exit.(33, 38)

Dean describes the choice and voice rationale for patient participation as collective individualism.(33) This is based on the neoclassical health economic consumer choice theory.(178) This theory describes three assumptions to explain decisional behaviour:

1. Utility maximisation: People (consumers) will act (make decisions) to maximise their utility (desired health status) through the consumption of goods (healthcare).
2. Rationality: People (consumers) always behave rationally (act in accordance with their desires).
3. Self-interest: People (consumers) are non-satiable (they always want more).

Consumer choice theory has been criticised for being overly simplistic and failing to take into account altruistic behaviours.(178) However, it is still influencing health policy as patients are framed as participating by rationally choosing services which maximise their utility, based on their individual preferences.(33) In a competitive market, services, including general practices, compete for patients based on patient preferences. Therefore, services need to exert effort in understanding and acting on patient demand and preferences, and this promotes service improvement.

In order to understand patient preferences, health policy has promoted collecting patient satisfaction data in the form of patient experience surveys, on the grounds that if services are satisfactory they are meeting patients preferences (see Chapter 1).(86, 88, 89) Patient experience surveys provide information on individuals' feelings about services which can be measured over time and can be used to compare services and improve services.(183, 184) Surveys have advantages over focus groups or interviews because they can reach a wide population efficiently. GPs have described patient experience surveys as subjective, emotional, not scientifically robust, and not locally relevant, and they rarely act on the data.(83, 86, 88, 89) This is unsurprising if the purpose is to make general comparisons across services to encourage competition. In order to make decisions about local resource allocation, especially when resources are limited, decision makers need information about the relative value local patients place on different aspects of services.(183, 184) This information is not contained within patient experience surveys. In contrast, prioritisation tasks, such as DCEs, are informed by consumer choice theory.(178) They force people to weigh-up the costs and benefits of different services and make choices and trade-offs.(184, 185) This leads to a closer approximation of how much ‘value’ people place on specific service characteristics or attributes.(176, 186) By assuming that people act rationally, in self-interest, to maximise their utility, then by studying their decisional behaviour the value of different services can be derived.(178) This mode of inquiry is described as positive economics and has its roots in positivism. It is assumed that individual utility can be measured and the sum of individual utility is equal to the collective utility of a population.(33, 178) This is clearly problematic to interpretivists who believe more than one reality can exist and subjectivity is important. However, when compared with passive patient experience surveys, patient preference surveys assume patients have agency to make decisions, and this is more consistent with a PAR paradigm. In addition, preference data is explicitly subjective, directly asking people to give their opinions.(183, 184) If a scientifically valid measure can be produced for use at a local level, a preference survey may negate the current criticism that GPs have of patient experience surveys. Therefore, rather than using a prioritisation survey within a choice and voice rationale, this projects rationale for using a prioritisation survey is to widen local participation and recognise patients as capable decision makers.

In summary, GPs as independent contractors have the power to make some decisions about the allocation of resources to different aspects of general practice services.(92, 93, 179) They do not always make the same decisions as patients.(101, 118, 119) Policy views healthcare as a market in which different services (general practices) compete for participating patients by aligning their services to patient preferences.(33, 38) However, the current mechanisms of discovering patient preferences via patient satisfaction and experience surveys are not working.(83, 86, 88, 89) An alternative is patient preference methods which frame patients as rational decision makers with agency.(176, 178, 184-186) Therefore, the intervention in this project aims to increase patient influence by reframing PPGs as local policy makers, making decisions based on population level patient preference data derived from a DCE.

2.8 Ethical considerations

A key validity criterion for participatory research is that it is judged by those participating in the research as ethically valid.(108) Therefore the ethical principles of participatory research are determined by the underlying values of democratic participation and equal partnerships between those conducting and those affected by the research.(187) Participatory research encounters similar ethical issues to other approaches, but three issues are more pronounced due to increased participation:(187)

- Managing expectations. Expectations were constantly negotiated with the co-research group. Some people left early in the project as it did not meet their expectations. Our partnership agreement acknowledged that different people would have different contributions depending on their skills and resources. We agreed to treat all contributions equitably.
- Power and control. The project was limited by external funding commitments, PhD requirements, and the institutional culture of academia. Our partnership agreement attempted to ameliorate some of these limits and we regularly reflected on their impact.
- Sharing public experiences and maintaining confidentiality. The partnership agreement stressed the importance of maintaining confidentiality regarding research data. The balance between participating in dissemination and maintaining anonymity were regularly highlighted and discussed.

The ICPHR describe seven principles of ethical participatory research (Table 2.4).(187)

I applied for ethical approval in two phases: for the development of the intervention, and for the evaluation. This was to ensure the CRG had the opportunity to influence the design of the evaluation, in light of the emerging intervention. A NHS Research Ethics Committee reviewed the study and advised that according to their criteria it was service evaluation. Therefore, I successfully applied to the University of Leeds Medical Research Ethics Committee for approval for both phases of the study MREC16-025 and MREC18-009 (Appendix 2 and 25).

Table 2.4. Ethical principles of participatory research and their application.

Principle	Description	Application within the co-research group
Mutual Respect	Research relationships are based on mutual respect and active listening.	Co-researchers were offered payment for their work, expenses, and co-authorship. Everyone was offered the same payment irrespective of their role outside the group.
Equality and Inclusion	Strengthen the voice of seldom heard groups, and challenge discrimination.	Recruitment to the CRG aimed for diversity of skills, experiences and backgrounds. Particularly people who work with a wider network of people.
Democratic participation	Equal voice in decision making and regular reflection on power dynamics.	A partnership agreement was co-designed explicitly outlining our approach to consensual decision making and voting if needed (Appendix 8). Meetings were co-chaired.
Active learning	Encourage reflection and involvement in interpreting research findings.	Reflection, including on power, was encouraged in each meeting and annually. Co-researchers were involved in interpreting the findings and reflecting on the implications for policy and practice.
Making a difference	The overarching aim should be to enact change.	Co-researchers have been involved in disseminating the findings.
Collective action	Stakeholders work together to achieve change	The group included patients, clinical and administrative staff, local policy makers, and researchers, all working together.
Personal integrity	All participants are responsible for their actions and behaviour.	The partnership agreement highlights the whole research teams' responsibilities, including the importance of reliability, trust, honesty, transparency and confidentiality.

2.9 Summary

This chapter has outlined participatory research as an explicitly ethical research paradigm with the key principle being the participation of those affected by the subject of the research throughout the research. Participatory research views reality as relative and socially constructed. Therefore, guided by PAR as my methodological approach I have worked with a multi-stakeholder co-research group throughout the project. PAR has a pragmatic approach to methods as long as they are consistent with the participatory principle. Therefore, I have outlined my rationale for combining PAR with the sociological theory NPT, and a DCE as a patient prioritisation survey influenced by economic theory. Details on the specific methods used to design the intervention to strengthen patient participation in PPGs are found in Chapter 3, the development of the DCE in Chapter 4, and the intervention field testing in Chapter 5.

3. Intervention Development

This chapter describes the development of the intervention to strengthen meaningful patient participation in general practice service improvement. The intervention consists of two participatory mechanisms: *partnership working* between patients and staff in facilitated meetings to adapt, delivery, and act on a prioritisation survey; and *consultation* with the wider patient population using the prioritisation survey. These participatory mechanisms were developed in parallel (see Section 2.5.2.4).

This chapter focuses on the development of the *partnership working*, specifically the development of intervention meetings between PPG members and staff, building on the existing literature discussed in Chapter 1. Intervention development took a participatory action research (PAR) approach (discussed in Chapter 2). Therefore, the design of intervention meetings was generated experientially by working together as a co-research group (CRG). This involved planning, collecting, and analysing primary data for the development of the prioritisation survey, whilst critically reflecting on our experiences of working together to inform the design of the *partnership working* intervention meetings. The details of the development of the *consultation* prioritisation survey are described in Chapter 4.

3.1 Intervention overview

Chapter 1 outlined the challenges faced by PPGs, namely role confusion, representation legitimacy, and power. To recap, the intervention aimed to address these challenges by combining two participatory mechanisms: *partnership working,* and *consultation*. Utilising these mechanisms in combination also satisfied the three theoretical constructs required for public participation in priority setting identified by Bovin and colleagues (102):

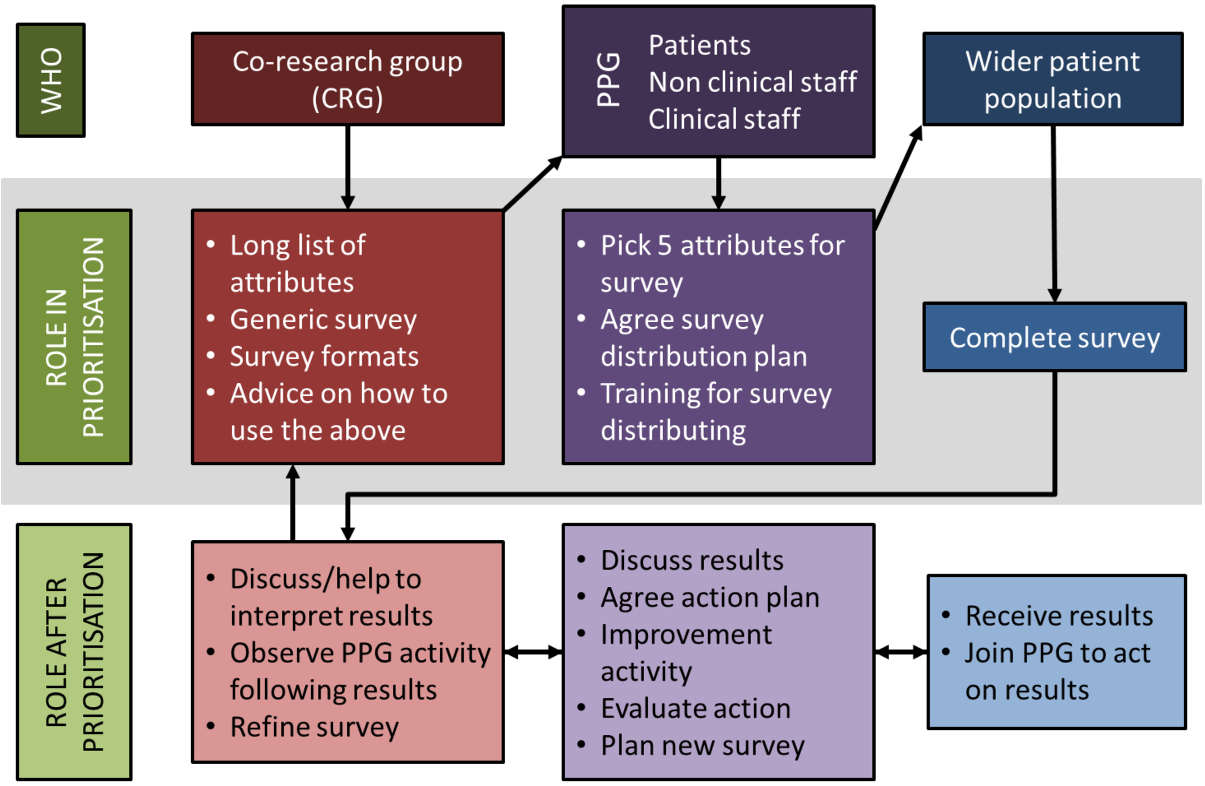
- A mechanism of partnership working providing PPG members with **credible knowledge** about the wider features and organisational constraints of general practice, and opportunities to use this knowledge to influence service improvement decisions.
- A legitimate method of consulting the wider practice patient population about their priorities, aiming to achieve **statistical representation** through a survey. This aimed to raise wider awareness of the PPG increasing recruitment, and hence **representational legitimacy** of the PPG.
- A safe deliberative space, **ameliorating the effect of power** through the use of participatory methods and facilitation.

These three adapted constructs informed the pre-development structure of the intervention the CRG would field test working with two general practice PPGs (Chapters 5-7):

- Partnership working in one or two meetings with patients and staff to adapt a pre-designed prioritisation survey;
- Support to conduct a consultation with a representative sample of the patient population through a prioritisation survey;
- A follow up meeting with patients and staff working in partnership to develop an action plan based on the results.

This chapter describes the process of developing the aspects of the intervention which support the participatory mechanism of *partnership working* between PPG patients and staff. Specifically, the development of the meeting content and structure which formed the final intervention which was then field tested with two separate general practice PPGs (Chapters 5-7). These meetings were designed to support the PPGs, including staff, participating in the intervention field testing to pick five attributes, distribute the survey, and discuss and agree an action plan. Figure 3.1 outlines the relationship between the work of the CRG developing the intervention (red boxes), and the work of the two PPGs field testing the intervention (purple boxes), and surveying their wider practice patient population (blue boxes).

Figure 3.1. Relationship between the intervention and the CRG, field testing PPGs, and their wider patient population.



3.2 Intervention development methods

The key principle of participatory action research (PAR) is that stakeholders should participate in all aspects of the research.(24, 108, 146) In addition, the intervention design approach incorporated key principles of complex intervention design guidance including being dynamic, iterative, creative, open to change, and looking forward to evaluation.(126) It also incorporated several of the actions recommended in the guidance including (126):

- The intervention was based on the existing literature and Boivin's three theoretical constructs of public participation in priority setting.(102)
- The co-research group (CRG) comprised different stakeholders and was established to lead the intervention development (see Chapter 2, Section 2.5.2).
- The CRG drew on their own experiences of PPGs, supplemented with primary data, to test our theories and materials, harnessing experiential learning. This helped to ground the intervention in the complex adaptive system of general practice with the aim of changing systemic patterns.(143, 144)
- We utilised normalisation process theory (NPT), an established implementation theory (see Chapter 2, Section 2.6), to identify potential implementation facilitators and barriers at an early stage, and to attempt to mitigate them.
- The PAR approach explicitly encourages iterative cycles of development and learning.

3.2.1 Primary data collection

As discussed in Chapter 2 (Section 2.5.2.4 and Figure 2.2) intervention development involved three sub-phases of work. Therefore, primary data contributing to intervention design was generated from three sources:

1. CRG meetings to develop the prioritisation survey and critically reflect on collaborative working. CRG meeting discussions were audio-recorded and relevant sections of the discussions were transcribed. Meeting documents, materials generated through participatory methods, and field notes were also generated. (Section 3.2.1.1)
2. Focus groups with five PPGs and one practice team to obtain feedback on the prioritisation survey, and the content and structure of intervention meetings. These were audio-recorded and transcribed verbatim. Reflexive field notes were also produced. (Section 3.2.1.2)
3. 'Think aloud' interviews with the general public as part of piloting the prioritisation survey. Respondents were recruited from a local involvement organisation (Healthwatch). The interviews were audio-recorded and transcribed verbatim.

Reflexive field notes were produced. (Section 3.2.1.3 and Section 4.6 for detailed description of the sample)

The next sections will describe the data collection from each source in more detail. I will then describe the integrated qualitative data analysis.

3.2.1.1 The co-research group

The CRG is a multi-stakeholder group including patients and staff interested in strengthening patient participation in general practice service improvement. Details of the composition of the group and the co-operative inquiry approach are discussed in Chapter 2. In summary, the CRG met to discuss cycles of problem identification, planning, action, and reflection. Through deliberation co-researchers were able to share, challenge, and reflect on different perspectives. This provides validity through exploring different ways of knowing the world: experiential knowing, presentational knowing, propositional knowing, and practical knowing.(113, 115, 147) This generated data and allowed reflection on the data generated. For instance, the CRG were involved in planning and conducting the focus groups and survey pilot discussed below. This generated practical and experiential knowledge about working together which supplemented the primary data from these activities.

To develop the intervention (partnership working and consultation), the CRG met nine times over 3 years, for approximately three to four hours per meeting. There were an additional eight task and finish groups who worked on specific tasks. Initial meetings focused on understanding the project and developing a way of working together. Later meetings focused on designing the intervention meetings and the prioritisation survey. The work of developing the prioritisation survey was completed in three stages (detailed in Chapter 4, also see Figure 2.2):

- Developing a list of attributes and template survey (three task and finish group meetings),
- Focus groups with PPGs and practice staff (five task and finish group meetings),
- Piloting the survey (two co-research group meetings).

Table 3.1 summarises the content of each meeting. Participatory methods were used in nearly all the meetings (see Table 2.2 for a detailed explanation). These methods were used to help structure meetings. This enabled the group to experience and reflect on their use, and assess their suitability for, and adapt them to use within the intervention.

Table 3.1. Co-research group meeting dates and content.

Name of meeting	Date of meeting	Content of meeting
CRG1	22/01/16	Introductions to each other Creative warm up exercise* – draw how you got involved Introduction to the project Meeting evaluation discussion
CRG2	16/2/16	Introductions to each other Creative warm up exercise* – what you hope to learn from the project Project overview and discussion of issues Meeting evaluation discussion
CRG3	8/6/16	Creative warm up exercise* – whose shoes Designing a partnership agreement and how we work together
CRG4	16/11/16	Update Flexible brain storming* 'features of general practice' and 'What is the problem PPGs are trying to address' – two separate sticky note maps produced. Speed evaluation*
TAFG1 M1	11/1/17	Continue flexible brain* storm of features of general practice Card sort* to start grouping features/sticky notes
TAFG1 M2	8/2/17	Looking at other frameworks – existing systematic reviews Card sort* to group features/sticky notes into categories
TAFG1 M3	22/3/17	Complete card sort* grouping of features/sticky notes Discussion of whether further input is needed
CRG5	26/4/17	Overview of progress Discussion of, and voting* on, long list of features of general practice Overview of prioritisation survey methods Speed evaluation*
TAFG2 M1	29/9/17	Review of possible survey design features – small group work Matrix* of different survey delivery formats Voting* on survey delivery formats
TAFG2 M2	3/11/17	Opportunity to try out first draft of the survey in multiple formats Feedback discussion regarding first draft of survey Feedback discussion on the list of features
CRG6	10/1/18	Review of survey format and list of attributes - in pairs Discussion to plan the focus groups Feedback on the CRG so far – charting* sticky notes on NPT constructs Speed evaluation*
TAFG2 M3	28/3/18	Early feedback from focus groups – flexible brain storm* 'analysis' of key issues Review updates to survey and list of features Review of intervention
TAFG2 M4	25/4/18	Inductive analysis in pairs – flexible brain storm*

TAFG2 M5	25/5/18	Deductive analysis using NPT constructs – flexible brain storm* and charting* Review of survey and list of features.
CRG 7	1/8/18	Review survey and list of features Outline of intervention meetings and evaluation Development of a matrix* for sampling intervention practices Vote* on criteria for sampling intervention practices Review voting method in intervention voting meeting Speed evaluation*
CRG 8	19/9/18	Reviewing of function, structure, and content intervention meetings – charting* what might happen in meetings using sticky notes Discussion of ethnographic research methods Speed evaluation*
CRG 9	14/11/18	Pilot survey analysis – individual work and group discussion Update on field testing recruitment Speed evaluation*

CRG = co-research group meeting. TAFG = task and finish group. M = meeting.
*= participatory method – for detailed explanation see Chapter 2 Table 2.2.

3.2.1.2 Focus groups with PPGs to test emerging intervention materials

Focus groups were conducted with PPG members and practice staff as the target population for the intervention. The aim of the focus groups was to get iterative feedback on the survey design and the card sort participatory method to structure discussions about adapting the survey (for full description of card sort see Table 3.3 later in this chapter).(151) A focus group is a small group of people brought together to discuss a particular topic, usually pre-defined by a researcher.(104) Unlike interviews, focus groups generate data on the social interactions within the group as well as content about the topic.(104) (188) Focus groups are normally comprised of between 6-12 participants, and last for 1-2 hours.(104) This is the usual size of a PPG and the usual length of PPG meetings.(75) We aimed to have a co-researcher co-facilitate each focus group, but due to practical constraints this only happened twice. Focus groups were audio recorded and transcribed verbatim. Where possible all co-researchers, including myself, produced reflexive field notes after each focus group.(104) Field notes focused on the nonverbal interactions, and the events around meetings.(104) Field notes, especially from multiple researchers, provide validity by allowing triangulation of data sources with the transcripts.(189, 190)

Recruitment was via co-researchers' network of contacts with local PPGs which was both pragmatic and convenient.(104) This is a strength of the PAR approach in which recruitment is often increased through gate keepers, and pre-existing trust relationships.(24) Within this network we aimed for a maximum variation approach in terms of PPG role, practice demographics, and how established the PPG was (Table 3.2).(104) All PPGs were contacted in advance via a gatekeeper who was either a PPG member or practice staff. The gatekeeper was asked to share information about the project, the participant information sheet, and consent form in advance (Appendix 9 and 10). At the start of the focus group this information was shared again and informed consent obtained.

Table 3.2. Focus group descriptions.

Focus group (FG)	Location	Practice deprivation score IMD*^	Size of practice *	Practice ethnicity* (w=white)	No. of patients	No. of staff (roles)	Other
FG1	Manc	18.3	13,992	81.4% w	5	2 (PM and receptionist)	CRG co-facilitation
FG2	Leeds	27.8	8,387	67.4% w	8	1 (Receptionist)	
FG3	Manc	44.1	7,787	85.3% w	5	1 (PM)	
FG4	Manc	45.9	10,445	86.9% w	9	2 (GP and PM only present for the start and end)	Patients only. First PPG meeting
FG5	Leeds	54.9	6,794	90.2% w	0	12 (4*GPs, 3*nurses, 1*PM, 4*admin/ reception)	Staff only
FG6	Leeds	16	11,177	85.7% w	4	1 (PM)	CRG co-facilitation

**Data from Public Health England: National General Practice Profiles [accessed 5th March 2020].(148)*

^IMD = Index of Multiple Deprivation (Official English government measure of deprivation of small local areas based on income, employment, health, education, housing, crime, and environment indices). Higher number indicates greater deprivation.(149)

Six focus groups were conducted. Five were held with PPGs (four with patients and staff, one with patients only), during regular meetings. One group was held with practice staff during their regular practice meeting. We used existing groups and meetings for the following reasons:

- Arranging a meeting with an existing group was easier than recruiting a new group.
- To observe the social interactions and decision making processes in PPGs.
- To explore implementation barriers and facilitators with the target population.

As we were using existing groups we did not ask PPG members or staff for their demographic characteristics as this may have changed the dynamic of the meeting. Observational notes included subjective interpretations of age, gender, and ethnicity. However, as these are subjective and may affect anonymity they are not reported.

3.2.1.3 Think aloud interviews with people completing the pilot survey

The pilot survey is discussed in detail in Chapter 4. In summary, 30 people took part in piloting the survey, 15 of these people also took part in ‘think aloud’ interviews. ‘Think aloud’ interviews are interviews conducted whilst the respondent completes the survey.(191) An interviewer prompts the respondent to “say what you are thinking” whilst they complete the survey.(191) I conducted the interviews with one of the co-researchers, and produced reflexive field notes.

3.2.2 Data analysis

Qualitative analysis proceeded concurrently with data collection.(104, 192) This enabled testing and sense checking of emerging findings and opportunities to seek disconfirming data increasing validity.(189) Data from all three sources was analysed together, using a constant comparison approach to compare within and between data sources.(104, 192) Triangulating different data sources increases reliability.(189, 190) The data was organised and managed using NVivo software.(193) A mixed deductive and inductive thematic analysis was used.(104, 194) The deductive approach drew on the four theoretical constructs of NPT: coherence, cognitive participation, collective action, and reflexive monitoring (see Chapter 2, section 2.6).(168, 195) For the CRG meeting data this analysis focused on the relationship work between patients and GPs in the CRG, and what could be learned from this for the intervention development. For the focus group data this analysis focused on the work of collective decision making and the interactions between group members. For the interview data this analysis focused on the work of completing the survey and making decisions. Inductive analysis sought disconfirming data and explored emerging themes outside of the NPT framework, with particular attention to power and representation.(104, 189) Inductive thematic analysis of the focus group and interview data also explored participants’ feedback regarding the survey design and features of general practice. These themes were descriptive and related to the sections of the survey and the different features.(104, 194) These results are discussed in Chapter 4. I led the thematic analysis and familiarised myself with the data by reading and rereading transcripts and meeting notes.(194) I shared my emerging reflections in CRG meetings and with my supervisors to check my understanding, increasing reliability.(189, 194) Sharing reflections with the co-researchers, on the CRG meeting data enabled a form of respondent validation, and encouraged deeper reflection and propositional knowing within the co-research group.(104, 189, 192) The CRG also read focus group transcripts and exerts from the pilot survey interviews. Themes were discussed in three analysis focused CRG meetings (Table 3.1, TAFG2 M4, TAFG2 M5 and CRG 9). Following the first two meetings, and drawing on our previous discussions of emerging findings, I developed an analysis framework and coded the existing and emerging data.(194)

3.3 Findings

Results are presented below using the four theoretical constructs of NPT: coherence, cognitive participation, collective action, and reflexive monitoring.(168) Results **highlighted in bold text** represent actions taken based on the findings. Where quotes have been altered for clarity, brevity, or anonymity, alterations are signified by square brackets []. Co-researchers are identified by their initials. Focus group participants are identified by number.

3.3.1 Coherence

3.3.1.1 Articulating the aims and boundaries of the intervention

The CRG was deliberately established to represent a wide variety of stakeholders with different experiences of PPGs. In early meetings it became clear that individuals had widely different ideas about the collective aim of the intervention, informed by their perceptions of the role and value of PPGs. The CRG were unclear about the 'problem PPGs are trying to address' and this was a barrier to collective work on intervention development. Therefore, we undertook a 'flexible brainstorm' to identify the role of PPGs, revealing 27 different role framings (see figure 2). Through this exercise we developed a communal understanding of the complexity of the potential roles of PPGs.

Figure 3.2. Illustration of flexible brainstorm about the problem PPGs are trying to address

Specifying that there are different roles of PPGs, and articulating a rationale for why we were focusing on addressing one of these roles (service improvement), allowed individuals to weigh up the value of taking part in the project.

Reflecting on this led us to develop a 'description of the process' document (Appendix 13) which specifically outlined the role of the intervention as helping PPGs to be involved in decisions about service improvement. We used this when approaching PPGs and practices to take part in focus groups.

The focus groups demonstrated that the multiple aims, roles, and values of PPGs discussed by the CRG, were also reflected in wider PPGs. FG2 wanted to support their practice; FG6 focused on identifying and raising issues for the practice to address; FG3 were looking for inspiration about their role; and FG4, meeting for the first time, wanted to be told what to do. Therefore the intervention needed to recognise this variability in PPG roles, and be clear and specific about its aims. **As a result, we designed 'Meeting 0' for the intervention field testing practices to emphasise the importance of clarity about the intervention. This aimed to allow practices and PPGs to understand the intervention, how it is different from their normal practice, and make an informed decision about whether to take part, or not, based on their perceived value of the intervention.**

3.3.1.2 No collective specification of general practice

Throughout the intervention design process there was uncertainty about the definition, purpose and boundaries of general practice. This uncertainty was around both individual and communal specification, and both had an effect on the intervention development.

The communal specification of general practice within the CRG affected the boundaries of our definition of general practice service improvement, and hence intervention development. As a GP, I had a concrete understanding of general practice related to the work done by GPs within a general practice building or organisation. I had assumed this definition was communal. Two examples demonstrate how my understanding differed from other CRG members, both patient and GP members.

Example 1. Screening abstracts for our systematic review (Chapter 4) with a patient co-researcher. When checking agreement titles and abstracts, I realised that she included papers where general practice was the setting rather than the object. As a result we modified our criteria, refining the meaning of general practice and boundaries of the evidence we were seeking, leading to a closer agreement on papers.

Example 2. A GP co-researcher, who was also a commissioner, argued that due to funding constraints, the definition of general practice needs to broaden. As a result, he felt PPGs should focus on activities around self-care and social prescribing, providing a link between a general practice and their wider community. This affected the scope of our discussions around the features of general practice.

In both examples, deliberation raised different individual specifications and enabled communal understanding to develop. **This emphasised the importance of the intervention meetings allowing space for deliberation, especially for issues where there is uncertainty and variation in the individual specification.**

3.3.1.3 Insights into internalisation

For an intervention to be successfully implemented, stakeholders must see value in the intervention. The intervention focuses on patients participating in the prioritisation of service improvements based on what patients' value about general practice. Therefore, intervention development explored how people make value judgements.

Example 1. CRG members picked the ten features they thought were most important about general practice. Everyone picked from slightly different perspectives:

- *MK picked based on those that were most important to him.*
- *ZN (a GP) picked which were important to her as a patient not a GP.*
- *AD picked those she had experience of and struggled to value things that she did not have experience of, like home visits.*
- *RM picked at first based on her individual needs and then thought about which of these would be most important to her community.*
- *PG picked considering the wider community which he represents*
- *RC picked attributes from a standards point of view – thinking about her role preparing health practitioners for a professional role. She picked one about making appointments for herself.*

Meeting notes from Co-research group meeting 5

Many chose based on their experience of general practice. However, some picked features for other reasons, influenced by their individual understanding of their role in decision making. This included the GP who picked features based on her experience of being a patient, rather than a GP.

Example 2. In all the focus groups there were examples of individual participants sharing experiences and the group forming judgements based on collective experiences. Participants were much more vocal about features that they had experience of, and their experience provided them with credible knowledge to discuss these features.

Example 3. In the pilot survey, when forced to make a choice, decisions were based on personal experience. However, in a few cases where the individual did not have direct experience of the features in the survey, their decisions were based on social justice arguments: what would be best for the wider population.

> *"I'm going to tick A, because* [of the attribute] *'Priority given to patients with extra needs', cause none of the others I don't think would affect me anyway." Think aloud interview P28*

Decisions appeared more difficult when respondents were forced to choose between personal preferences, and social justice preferences. One participant was frustrated when he felt forced to choose between better interpretation services and features that suited him such as 'more support' and Skype consultations:

> *"There are 'more support', so I think that's really good, this is, you know, it's empowering patients, which is really good. And it's got that* [Skype consultations] *on. I'm gutted that you had to lose that* [Interpretation services]*, but… this is, you know, benefit to me." Think aloud interview P19*

The examples highlight the link between experiences and preferences. Preferences were almost always grounded in experiences, and experiences provided credibility when individuals were trying to persuade others of their position. The examples also demonstrate the importance of framing instructions around decision making: what criteria decisions should be based on, and why the decision makers' perspective is important, as well as others. **As a result of these reflections, the instructions for the survey, and intervention meetings included framing of the decision making process.**

3.3.2 Cognitive participation

3.3.2.1 Enrolment and legitimacy of involvement

Enrolment and commitment to the work of PPGs is strongly related to the perceived legitimacy of that role, both internally and by other stakeholder groups. Patient co-researchers wanted evidence of their role being legitimate to staff, especially GPs, before committing to the work. GP co-researchers struggled to internally legitimise their own role in a 'patient group' process, and this affected their commitment.

Example 1: Enrolment to the CRG and GPs internalised legitimacy. Patient co-researchers were enthusiastic about opportunities to improve the function of PPGs. GPs were much harder to recruit and expressed several reservations including refusing to work with their own patients, and needing reassurance there would be more than one GP in the group. The four GP co-researchers who participated in intervention development were mainly motivated by the opportunity to get involved in research, rather than the patient participation content of the research. Therefore, it is unsurprising that they appeared to lack internal legitimacy about their role. This was demonstrated in the earlier example of the GP voting based on her experience as a patient rather than a GP. In an email after the meeting she explained that she thought the project was about 'patient involvement' and therefore her contribution should be as a patient, rather than a GP. Another example, was a reflective exercise on roles within the CRG, 18 months into working together. The GP in the meeting announced that he had only just realised what his role in the group was:

> *GP: After having to listen to what everyone else's role is I understand what my role is now.*
> *[Laughter from the group]*
> *JD: Go on.*
> *GP: So I am obviously here to represent how this would go down in, from the general practice point of view.*
>
> *Co-research group meeting 6. 10.01.18*

Although these examples relate to legitimacy of being involved in the CRG, there are parallels between the CRG and PPGs as multi-stakeholder groups. **Therefore, the intervention we field tested highlighted the importance of the GPs role in *shared* decision making.**

Example 2. Single stakeholder focus groups expressing the desire for legitimisation from other stakeholders. FG4 was a patient only focus group, and FG5 a staff only focus group. FG4 took part in the research as an opportunity to set up and get advice on running a PPG. Therefore, prior to the start of the meeting I facilitated introductions and a discussion about motivations with the GP partner and practice manager present. This was to demonstrate to the patients that the PPG was valued by the practice staff. After this discussion, I asked the GP partner and practice manager to leave, before starting the focus group activity. However, the patients expressed annoyance about this related to the legitimacy of their role:

> *Participant 7:* […] *I actually don't know all the names of the doctors anymore!*
> *Participant 4: Yes that's why I think one of them* [a member of staff] *should be present at the meeting.*
> *Interviewer: Today?*
> *Participant 4: I do actually. Yes.*
> *Participant 1: I think it's, that there should be somebody representing the practice*
> *Participant 4: Yes.*
> *Participant 1: In the meeting just to make sure that we don't just go down the route that, at the end of the day, you say well actually we already do that! Or actually*
> *Participant 9: You can't do it! Yes.*
> *Participant 3: It isn't feasible to do it.*
>
> *Focus group 4*

FG5 was a mix of different staff (Table 3.2). The card sort activity prompted a discussion of, and interest in patients' interests and preferences. When reviewing the draft survey they described why it was legitimate for patients to complete it:

> *Participant 9* [GP]*: I think the trade-off is interesting.* […] *You know that we can't do everything and if we do one thing we might, you might lose something else! Rather than just more, more [laughs] and, and yes and I think it puts a little bit back onto them* [patients] *as well*
> *Participant 10* [Practice Manager]*: Absolutely yes.*
> *Participant 9: that it's their* [patients] *choice and their* [patients] *decision and a bit, a bit more ownership of it.*
> *Participant 10: It's just about them* [patients] *understanding it's their NHS and they* [patients] *have to try and manage it as best as possible. It's not just us!*
>
> *Focus group 5*

The above examples demonstrate that both patients and staff see value working together. Patients wanted staff present to provide credible knowledge of the functioning of the organisation. Staff were interested in patients' views and felt it would make their decisions more legitimate if patients understood the constraints in which decision making happens. **Therefore, the intervention emphasised that legitimacy is based on working together, rather than one group working alone.**

Example 3. Emphasising GP involvement as legitimate to maximise GP enrolment in the intervention, which in turn legitimises the intervention. Reflecting on the above two examples, the CRG had a number of discussions about how to motivate GPs to take part in the intervention. In one meeting, a GP co-researcher argued that GPs would only take part in the intervention and allow the survey to be conducted, if they felt the survey asked questions that they could act on.

> *GP: So ultimately* […]*, if you're trying to get your research stuff* [the intervention] *done you don't want to be chucked out the door. So you want to basically get the questions that you* [the PPG] *want to ask* [on the survey]*, if the GP disagrees with them, let's say like weekend* [opening]*, we* [the GP practice] *can't possible ask about weekends because we* [the GPs] *are not going to do it. It is then* [JD]*'s decision to persuade the GP that there may be a reason why you* [the PPG] *want to ask that and there may be other options to provide in your service, which you could act on. If they* [the GPs] *still say we ain't going to ask that question,* [JD] *isn't going to be allowed in the door. So I think ultimately it is a practicality thing,* […]
>
> *Co-research group meeting 6. 10.01.18*

This led onto a discussion about who has power to decide to take part in the intervention, and how to appeal to those with power when trying to enrol practices in the intervention.

> *MK: At our last* [PPG] *meeting,* […] *I said* […] *I would like to introduce this idea of a survey which I am working on with some other people* [the CRG]*. And I realised that I was saying it to the people who were going to do it* [the PPG] *rather than the people who were going to authorise it* [the GP partners]*. And I did think, I thought well I must say to them that I must raise this with the GPs that, in our practice, that, you know, do you have a problem with this? I mean I don't think that they will like to say that they find a problem, but they might.* […]
>
> *TF (GP): But once the patient participation group have decided what questions they want to ask they* [the GPs] *may look at one and go I'm not bloody well asking that in my surgery.* […]
>
> *MK: And is that reasonable?* […] *To me it seems that it is their practice as well as our practice, it is both, it is all of ours. And it would be, I just thought it is not facing facts if I don't say* [to the GPs] *is it ok if I do this?*
>
> *TF (GP): I think practically I think yes you should be able to send a questionnaire out whenever you want and not involve the GP, but that is not the reality...* […]
>
> *MR: And in terms of selling it to the GPs the fundamental thing is to be telling patients that they can't have everything they want.*
>
> *JD: Yes*
>
> *TF (GP): That is a great selling point.*
>
> *MR: I would have thought most GPs would think that is a very good thing to say.*
>
> *Co-research group meeting 6. 10.01.18*

As a result we agreed the approach to each practice would need to emphasise that practice staff would get a say in what would happen. We agreed we needed to make GPs feel like they have control over the process, but we also agreed that we wanted to push the limits of what patients could influence. **Therefore, intervention meetings were designed so all stakeholders have equal say. We also emphasised that decisions would be made in these meetings, and therefore GP partners should attend meetings if they wanted to influence decisions.**

3.3.2.2 Activation and power

Power was an important barrier to activation of collective equitable deliberation. This was demonstrated both within CRG meetings and focus groups.

Example 1. GP power within CRG meetings. There were subtle changes in the atmosphere of CRG meetings depending on who was present. One GP, who was also a commissioner, was observed to have a particular style in which he appeared to listen to everyone else, then summarise the content. Listening back to recordings of meetings, I reflected that his summaries often changed the content of the conversation resulting in his opinion being taken forward. This compared to the patient co-researchers who I observed had a different style of contributing:

> *When a person brings up a new* [feature of general practice]*, each time everyone reflects on the attribute from their own opinion, usually giving a personal story of how*

> *that* [feature] *has affected them. Often detracting from the original persons experience – therefore keep getting some competitive story telling.* [The GP commissioner] *also taking on the role of defending general practices when these stories come up.*
>
> *No one in the group is sure what they can/cannot talk about. The patients (even in this group) don't know how general practice works behind the scenes (does this matter?) and the GP in the meeting keeps putting up barriers around what patients can/cannot talk about.*
>
> *Researcher field notes following TAFG 1*

Example 2. Practice staff dominating focus groups. The power of individuals to set the agenda within meetings was also seen in the focus groups. In the four focus groups where both patients and staff were present, staff frequently shut down conversations.

> *Participant 3: Right so* [reads card with feature on it] *how long your appointment lasts.*[…]
> *Participant 1 Practice Manager: I think again* […] *that's going to depend on the type of appointment cos you might get someone coming to walk in. They're in and out in 2 minutes. 5 minutes. You might get someone else come in and they're in 15 or 20. Now the system's flexible enough to do that. But if… and we've also changed our routine appointments now to 15 … minutes so that people who are coming in for a routine, more complex one they've got longer. So…*
> *Interviewer: So it's not an issue for your practice?*
> *Participant 2: No.*
> *Participant 1: Well I think we've done a lot of work on it already.*
>
> *Focus group 6*

Practice staff would often speak first and state that the feature raised was not an issue at their practice, or nothing could be done about it due to resource constraints outside their control. This closed down the conversation. Anyone wanting to discuss the feature, had to say something nice or actively disagree, risking being seen as defensive or adversarial. **As a result of staff exerting control in both CRG meetings and focus groups, we designed separate card sort meetings for patients and staff in the intervention. This was to ensure patients had space to explore and exchange their personal experiences, activating this knowledge.**

Power asymmetry was also expressed between different PPG members in the focus groups. In FG2 and FG4 a married couple was present. Couples reinforced each other's experiences and opinions, giving their voices more time, space, and weight. In FG2 one woman was actively side-lined. She tended to be more critical of the practice, and often phrased her contribution in relation to the wider population experience. The rest of the group frequently disagreed with her and cut her off. **These observations reinforced the need for participatory methods in intervention meetings to structure discussion and equalise voice. They also raised concerns**

about who is present in and absent from intervention meetings. This strengthened the rationale for a population wide survey in addition to PPG opinions.

3.3.2.3 Representational legitimacy and whose voice counts

Representational legitimacy is a key issue for PPGs and was a frequent discussion within the CRG. Our discussions touched on and conflated statistical representation, democratic representation in the form of voting, the process of ‘being a representative’, inclusion, and social justice (giving greater voice to those who use the service more, and those who have the worst health). The focus groups demonstrated that PPG members are not statistically representative of the population; nor are they democratically elected, often being recruited by the practice through opaque processes; and observations from FG2 suggested PPGs are not always welcoming and inclusive. In addition, at the end of FG2, the staff member present informed me that she values the PPG members so much, she goes out of her way to enhance their experience. This suggests PPG members do not always have the same experiences as other patients at the practice, questioning whether they can truly represent the wider patient experience. Reflecting on this, the CRG expressed unease about representational legitimacy within the intervention and which patient voices would have influence. **These concerns were somewhat ameliorated by having a two stage prioritisation process: the PPG influencing the survey, ensuring patient experience influences its design; and the survey attempting to provide statistical representation and wider patient population influence into the eventual action planning.**

The CRG recognised the practical constraints around achieving perfect statistical or democratic representation. As a result discussions moved to inclusive processes and encouraging participants to think about the wider patient population. The focus groups and survey pilot demonstrated that people were more comfortable talking about features of general practice they had individual experience of, such as ease of making an appointment. They found it harder to discuss issues they did not have experience of, such as using interpreters or charging for letters of support.

> *Participant 9: Responding to patients requests for letters to support housing or benefit appeals. […]*
> *Participant 2: I have no experience.*
> *Participant 8: None whatsoever.[…]*
> *Participant 6: I work for a military charity and we send the form out to doctors if somebody might need a stair lift just to get the doctor to back it up. And we put on the bottom please don’t charge for this, don’t charge the patient. […]*
> *Participant 7 [receptionist]: So do you think it is an important thing for everybody or do you think that it is...?*
> *Participant 3: I think it is*

> *Participant 2: I think it's a strain with money*
> *Participant 7 [receptionist]: It is usually for benefits and things so. […]*
> *Participant 6: I think it is important isn't it, for those particular people.*
>
> *Focus group 2*

However, raising these topics, forced patients to confront their lack of personal experience and think about other patients' access to care**. Therefore, despite equity features not being top priorities, the CRG made a deliberate decision to include them in the intervention we field tested to attempt to influence the content of discussions. We hypothesised that this may encourage PPG members to consider their role as representatives of the wider practice population. The CRG also emphasised the importance of active welcoming facilitation of intervention meetings.**

The CRG's changing views about representation resulted in a reconceptualization of the purpose of the PPG distributing the survey. Initially emphasis had been on the PPG members increasing their visibility as a PPG recruitment mechanism. The hypothesis was that this would result in a wider and more statistically representative, and hence legitimate, PPG. However, the focus group experience above suggested that this might just result in more people talking about their own experiences. The experience of conducting the pilot survey think aloud interviews with a co-researcher, offered an alternative approach to representation. Reflecting on our experience of listening to the public talk about their experience, we discussed that conducting the survey might be an opportunity for PPG members to seek out, listen to, and then re-present back the experiences of the wider patient population. Emphasising this process during the intervention may provide patient PPG members with legitimacy about 'being a representative'**. As a result we designed an intervention training meeting focused on encouraging PPG members to talk to patients in the waiting room, especially people 'who do not look like you'. We also developed a reflective feedback form for PPG members to complete based on their waiting room discussions with other patients.**

3.3.3 Collective Action

3.3.3.1 Deliberation needs task focused action to stimulate confidence and ownership.

The action the intervention is trying to promote is primarily multi-stakeholder deliberation within meetings, resulting in shared decision making about secondary service improvement action. Participatory methods were a key mechanism of promoting collective action in the CRG meetings (Table 3.1). Through experiential learning of using participatory methods in meetings, the CRG were able to theorise and test (during focus groups) which methods would be useful during the intervention.

Example 1. Using participatory methods in the CRG meetings. The first three CRG meetings had an agenda, but no other structure. This resulted in free flowing discussion which was repetitive and inconclusive, especially on topics where there was little shared coherence. Meeting 4 signified a change in this process by structuring the deliberation using flexible brainstorming to produce material outcomes in the form of sticky note maps (Table 3.1). Partners reported that for the first time they felt like they were finally doing something:

> [MK] *felt that he was doing something today and making progress – he gave the example of writing on the sticky notes and then talking about what was said – he said "this is better than listening to someone tell you about it."*
>
> *Notes from meeting 4. 16.11.16*

A smaller task and finish group, followed up the work, developing the sticky note map. They met monthly, allowing the discussion to deepen and communal specification to develop. In meeting 5, co-researchers who had taken part in the task and finish group appeared to be more confident and focused, than those who had not. One patient co-researcher initiated a plan to test our progress on a wider audience, volunteering his PPG. This example demonstrates that through action the co-researcher had become invested in the project and was taking ownership over the progression of the work.

Example 2. Developing the card sort process during the focus groups. FG1 was unstructured and did not use participatory methods. As a result the discussion was commandeered by a few individuals, and we ran out of time. The participants fed back that they were unsure about the purpose of the focus group and the survey, indicating a lack of relational integration between the focus group and our aims. Learning from the apparent failure, we turned our list of features into cards which could be discussed in turn, encouraging collective decision making about each features' relevance for their practice. This exercise was used in the remaining focus groups with some small refinements. In contrast to FG1, the remaining focus groups expressed interest in their collective work, requesting a summary of the features they had chosen to work on after the focus group.

> *Participant 5: Are we going to ask our GPs? Or is that a step too far at this stage?*
> *Interviewer:* […] *I'll write this up and give you, send you a summary so you've got something. So and, and which* [features] *were in which pile.* […] *And send that out to you.*
> *Practice manager: Can you do that? Actually list the red, amber and greens?*
> *Participant 4: Yes.*
> *Practice manager: Cos I could circulate that at the very*
> *Participant 5: And get some feedback.*
> *Practice manager: And say* [to the GP partners] *what do you think?*

Focus group 6

Both examples demonstrate that collective action using participatory methods stimulated confidence, ownership, and commitment to future action. Using these methods over time, as demonstrated in the CRG, generated a positive feedback loop of increasing ownership. Therefore participatory methods were a key feature of the intervention.

3.3.3.2 Recognising different individuals' skills, and providing space and trust to enact them

Working with the CRG resulted in a multiplication of the number and diversity of skills available.

Example 1. Recognising skills and sharing responsibility within the CRG increased workability and relational integration. CRG meetings became more productive when other co-researchers took on significant roles within meetings. One co-researcher, an experienced and skilled chair, helped plan and then chair meetings. Another co-researcher took on the role of 'rapporteur' providing a written summary of each meeting. After our first analysis meeting, multiple co-researchers praised one person for her analysis skills. Everyone recognising different co-researchers' skills and practical knowledge, reinforced that they were essential to the process, and not just for their experiential knowledge. This in turn increased the confidence of individuals and ownership over the work. However, it has also resulted in co-researchers without clear roles related to their skills, lacking confidence about their contribution to the project. **Therefore, intervention meetings, were designed with opportunities for PPG members to demonstrate their skills and practical knowledge.**

Example 2. Experiential learning raises awareness of potential skills gaps. One of the participants of the pilot survey was visually impaired and struggled to read the survey. We had not anticipated this, and quickly recognised we needed a solution. The co-researcher conducting the pilot with me, suggested he try helping her complete the survey, role playing the situation as if he were a PPG member handing out the survey in the waiting room. This was extremely challenging. Reflecting on this, we recognised that despite observing people completing the survey, neither of us had completed the survey ourselves, and therefore struggled to explain it to someone else. **Therefore, the intervention training included PPG members experiencing completing the survey themselves, and role playing skills and strategies to help others struggling to complete the survey.**

The above examples demonstrate the importance of recognising skills and skill gaps within a multi-stakeholder group. The skills and gaps were only recognised through attempting practical action.

3.3.3.3 The context of variability and uncertainty in general practice, and limited practice resources

Co-researchers were clear that they wanted to produce something that is useful and used. This was challenging due to uncertainty about the future of general practice and variability between practices. **Therefore the intervention was designed to be flexible and adaptable to the local context.** All six focus groups found some card sort features relevant to their practice, despite considerable organisational and PPG structure and function variation.

Time was a persistent resource constraint in both CRG meetings and focus groups.

Example 1. Reducing the length of the card sort exercise. Energy levels during the focus groups noticeably deteriorated over time, and the last card sort feature was often celebrated. In FG2, when the meeting overran, the staff member was unable to stay. **As a result the CRG reduced the number of features in the card sort exercise after FG4. This was a pragmatic compromise between having a comprehensive list of features and getting staff to participate.** The final two focus groups completed the process faster and within their normal meeting length (50 minutes for the staff lunchtime meeting in FG5)

Example 2. Limiting the length of discussion in the voting meeting. The CRG were clear that staff, including GPs, should be present in the voting meeting. I argued that this meant the meeting needed to be complete within one hour. The CRG were sceptical about whether this would be sufficient to allow all PPG members and staff to speak. **As a result, we agreed to manage time equally in the voting meeting. Each person was allowed one minute to feedback their choices, this was enforced with a red card system. We agreed to monitor whether this had a detrimental impact on discussion.**

Time was needed for meaningful deliberation, and lack of time limited the content of, and potential contribution to, discussion. There are persuasive practical reasons for limiting meeting time: particularly longer meetings may result in the physical absence of staff, and reduced concentration generally. Shorter meetings meet existing organisational processes of the practice and PPG, but this may be at the expense of the quality of discussion.

3.3.4 Reflexive monitoring

3.3.4.1 Systemisation of reflection

The aim of the CRG, was to provide an opportunity for all stakeholders to reflect together on the work involved in working together. Multiple examples above demonstrate how this reflection was utilised to shape the intervention and reduce potential implementation barriers. Where the impact of reflection was visible and change occurred, the CRG appeared to take more ownership of the group and intervention. Therefore, we considered reflection to be an important facilitator of PPGs taking ownerships of the intervention and normalising the new way of working. However, in CRG meetings and the focus groups, we often ran out of time for detailed reflection. Where reflection was not structured into the meeting, it was often pushed out by competing content. **Therefore, at the end of each intervention meeting, participants were encouraged to complete speed evaluations (place a sticky note on a flipchart to indicate whether the meeting was good or bad, if possible with comments outlining their reasoning). This feedback was included in intervention meeting summaries distributed to PPG members.**

3.3.4.2 Reconfiguration

The basic intervention outline and funding was secured before the CRG formed. This was a problem as some co-researchers were unhappy about the prioritisation survey method. One co-researcher repeatedly stated that we should use qualitative interviews rather than "*a coercive survey*". She was frustrated at not being able to influence this, and at times disengaged from the project due to this. However, the CRG were able to make changes at three levels of the project:

1. The way we worked together. We co-designed a partnership agreement, and agreed different roles within meetings.
2. The intervention design methods. Co-researchers suggested using their own PPGs as focus groups, and helped facilitate the meetings. One co-researcher initiated role play within the pilot survey.
3. The intervention itself. Co-researchers insisted GPs be present in intervention meetings. They influenced the survey design (Chapter 4). They suggested separate patient and staff card sort meetings and managing time equally in the voting meeting.

Knowing their suggestions were valued and influenced the project, appeared to increase their confidence and ownership. **This emphasised the importance of the intervention being flexible rather than imposed on the PPG or practice.**

The importance of flexibility was highlighted in the FG4, the patient only focus group. During the card sort participants struggled to make decisions about the relevance of certain features of general practice. They felt they needed further information from the practice:

> *Participant 8: How are interpretation services provided? [Pause]* […]
> *Participant 6: I'd say amber. But it's a question that we should ask the practice and if its been decided then we should decide if its an issue.*
> *Participant 7: Yes I think we have to, yes I've no idea.*

> *Participant 1: It's the same as that one* [previous attribute about benefits],
>
> *Focus group 4*

As a result of finding two attributes that they needed more information about, they introduced a new pile called 'need more info'. They planned to discuss features in this pile with the practice staff before making a decision. Having the freedom to change the card sort process, based on their frustrating experience of not knowing how to answer, diffused tension, built trust, and allowed them to plan future work. **Therefore, although a detailed outline of the intervention was developed as a result of this process, the intervention was facilitated flexibly and we encouraged ongoing suggestions and adaptions from both the CRG and intervention practices.**

3.3.5 A description of the intervention

These findings were instrumental in shaping the intervention through experiential learning. The content of the intervention meetings are described below in Table 3.3 and the process is described in Figure 3.3. A full description of the intervention using the TIDieR guidance on describing interventions is in Appendix 14.(196)

Figure 3.3. Overview of intervention process

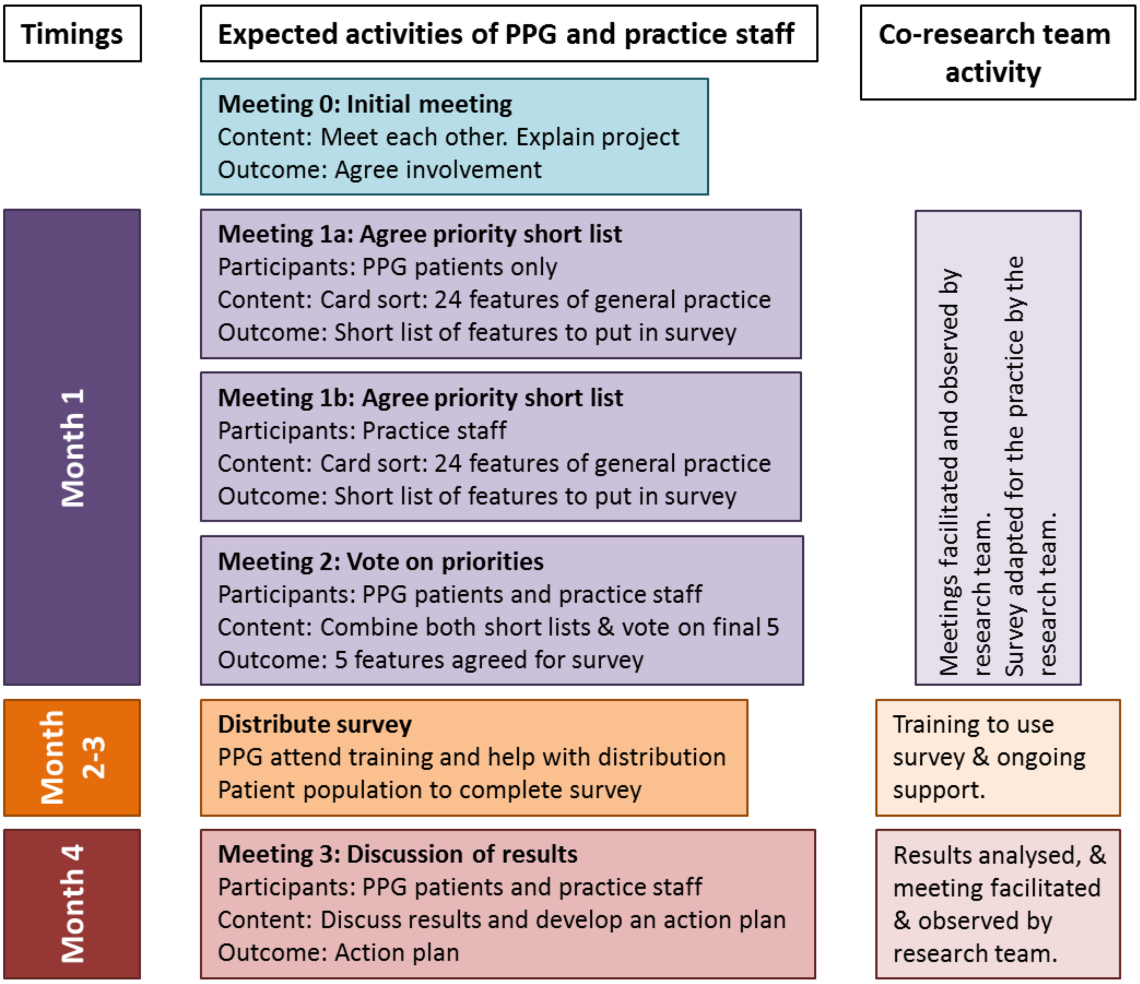


Table 3.3. Final content and structure of intervention meetings for the field testing

Meeting	Meeting content	Participatory methods used
Meeting 0: patients & staff	Introduce the project and CRG to the PPG	
Meeting 1a: patients only Meeting 1b: staff only	Meeting participants take it in turns to read out 24 cards each with a different feature of general practice. The group decide the card category: GREEN: 'yes, include in the survey, you'd be interested to know what patients think' ORANGE: 'maybe, include in the survey' RED: 'no, don't include in the survey, we wouldn't be interested or would not be prepared to change the feature'. Meeting finishes with review of the categories. Speed evaluation	Card sort – participants organise information on cards into different categories by consensus. Participants are encouraged to explain their choices. Speed evaluation – sticky notes used to obtain rapid immediate feedback on the meeting.
Meeting 2: patients & staff	'Green' and 'orange' category cards from meeting 1a&b discussed. All participants vote individually on their top 5 attributes using a voting sheet. Each person has one minute to discuss their vote. Scores are combined and discussed. Repeat voting. The five features with the combined highest score are chosen. Speed evaluation	Ranking, scoring and voting – to democratically and transparently agree on priorities. All participants have the same weight of vote. Voting is done together and participants are encouraged to explain their choices. Speed evaluation.
Training meeting: aimed at patients, staff welcome	All participants complete the survey to experience filling it in. Discussion of the survey Demonstration of handing out the survey using CRG members. Opportunity to role play in small groups. Feedback and reflections Discuss practical issues of survey distribution Speed evaluation	Role play – participants pretend to be in the situation they want to practice. Other participants provide feedback. Speed evaluation.
Meeting 3: patients & staff	Survey results sent out before the meeting for individual reflection. PPG members reflect on distributing the survey. Presentation of results and discussion. Action planning using flexible brainstorm Speed evaluation	Flexible brain storming – to generate and exchange knowledge interactively. Participants generate information and ideas on sticky notes which are displayed on the wall and can be moved around. Speed evaluation

Description of the participatory methods in this table was informed by (121, 150, 151) see also Chapter 2 Table 2.2.

3.4 Discussion

3.4.1 Summary

The PAR approach to intervention development enabled a collaborative, dynamic, creative and iterative design process grounded in experiential learning. The CRG worked through a number of action research cycles: identifying areas of work, planning the work, doing the work, and reflecting on and evaluating the work. This process included the co-researchers collecting primary data when they identified a need, and this was part of ‘doing the work’ of intervention design. This included discussions within co-research group meetings, testing out participatory methods, conducting focus groups, and piloting the prioritisation survey. Each of these areas of work provided knowledge that we could use in designing the intervention and the intervention itself. Using NPT as a framework to analyse this data, allowed us to focus on the potential implementation barriers and facilitators associated with the intervention. These are summarised in Table 3.4, along with the changes we made to the intervention to attempt to strengthen facilitators and pre-empt barriers to implementation.

3.4.2 Comparison with existing theoretical constructs

Our intervention design process and findings develop the theoretical constructs identified by Boivin and colleagues regarding patient participation in priority setting (Table 3.5). Boivin conceptualised the public as having credible knowledge, based on their lived experience, describing them as “experience-based experts”.(102) In our intervention, all participants, not just patients, are conceptualised as having unique and credible knowledge based on all four ways of knowing (113, 115, 147):

- Experiential – lived experience of being a patient or a member of staff,
- Presentational – being able to tell stories and share their experiences,
- Propositional – using their knowledge to prioritise and plan service improvements,
- Practical – collaborative working skills, change management skills.

Harnessing all four ways of knowing provides PPGs with greater credibility than focusing solely on individualistic experiential knowing. The four ways of knowing were illuminated by the CRG working together over time, in an ongoing process, utilising different skills. The focus groups demonstrated the need for a process enabling knowledge exchange. Staff have knowledge about how the work of general practice is organised, patients have knowledge about how the organisation of work is perceived and experienced. This is in keeping with Dean’s participatory mode of knowledge exchange, but extends this to acknowledge patients have more than experiential knowledge and the exchange is in both directions.(33) Therefore, our intervention conceptualised PPGs as action research groups, bringing together diverse individuals’ different ways of knowing, to build a collective knowledge about partnership working to improve services.

Table 3.4. Summary of findings and implications for the intervention design

NPT construct	Intervention development findings	Implications for intervention
Coherence	Multiple purposes and roles of PPG.	Meeting 0 and written material developed to emphasise the credibility and value of the intervention rationale: patient participation in service improvement decision making.
	Decision making is informed by the framing and context of the choice.	All decisions were carefully framed.
Cognitive participation	Barriers and levers of equitable participation differ by stakeholders and are influenced by power.	Separate card sort meetings for patients and staff, and participatory methods used to equalise voice. GP participation in meetings, and partnership working emphasised.
	There are multiple different conceptualisations of representational legitimacy.	PPG members reconceptualised as 'being representatives' by listening to patients whilst distributing the survey and re-presenting their opinions in Meeting 3. Equity features of general practice included to encourage PPGs to think about the wider population experience.
Collective action	Structured deliberation using participatory methods results in task focus, equity of voice, and commitment.	All intervention meetings structured using participatory methods.
	Recognising and utilising different skills and knowledge builds confidence and ownership.	Intervention meetings designed with opportunities to utilise PPG skills.
	Time is a limited resource.	Intervention meetings designed with a pragmatic compromise between length, content, and equity of voice.
Reflexive monitoring	Systematised reflection promotes knowledge exchange.	All intervention meetings include reflection.
	Flexibility allows reconfiguration and increased ownership.	The intervention encourages flexibility and adaptation.

Boivin and colleagues describe the public needing representational legitimacy.(102) In their intervention this was achieved through rigorous sampling and a survey providing statistical representation.(90, 102) They also discuss legitimacy developing through *'collective speech strategies',* a form of democratic representation. Our findings emphasised the importance of both patient and staff legitimacy, achieved by utilising multiple forms of representation. Patient representational legitimacy in our intervention is established through: a survey to address statistical representation; encouraging PPG members to 'be representatives', utilising the survey to engineer opportunities to talk to the wider patient population and deliberate on heterogeneous values (democratic representation); and focusing on inclusion by prompting discussions about equity and justice.(90) Prioritisation surveys conducted by parent-child dyads together, have been shown to provide useful opportunities for parents and their children to deliberate, exchange, and understand differing values.(197) In addition, GP partners and other staff being present in meetings was valued by patients as a form of symbolic representation related to their authority and influence over decision making.(90) Attempts at achieving statistical and democratic legitimacy in participation usually fail because they are based on the assumption that people with similar characteristics have homogenous views.(43, 44, 78) Combining forms of representation, with a clear rationale for each, potentially ameliorates weaknesses of the individual forms of representation, bolstering legitimacy.(28)

Finally, Boivin argues the public must have power to influence. They attempted to ameliorate the effects of power through meeting facilitation.(102) Our findings demonstrate that power is an issue throughout the process of patient participation and not just within multi-stakeholder meetings. This includes who judges the credibility and legitimacy of patients and their knowledge, how and when patient voice is heard, and which patient voices are heard.(35, 50) Therefore the intervention includes a number of approaches to equitable voice in decision making. These include participatory methods within meetings, facilitation, having separate meetings to activate collective patient experience, and encouraging the participation of powerful decision makers. The rationale is that if there is equity of voice within PPG meetings, this equates with what Arnstein defines as partnership working and hence meaningful citizen power.(36) Despite this the CRG had ongoing concerns about power and influence. PAR recognises that unequal power dynamics are inherent in all social interactions, and aims to illuminate these power differentials and their effect on change processes.(143) Therefore, by conceptualising PPGs as action research groups, and encouraging reflection, we hoped to expose the effects of power, and observe whether stakeholders are able to act on this.

Table 3.5. Extended theoretical constructs and practical implications.

Extended theoretical construct	Practical implications
All stakeholders have multiple **credible and different knowledge** to contribute. All different forms of knowledge (experiential, presentational, propositional and practical) are valued.	Knowledge exchange through multi-stakeholder discussion and PPGs working as action research groups.
All stakeholders have **legitimate roles**. Representational legitimacy of patients and staff is increased through different approaches to representation (statistical, democratic, and symbolic) and a focus on inclusivity.	Survey consultation to achieve statistical representation from the patient population. Democratic representation by PPG members 'being representatives'. Symbolic representation of decision makers attending meetings.
Power differentials exist within and between different stakeholder groups. Deliberative partnership meetings should aim for equity of voice.	Partnership working requires all stakeholders to meet together. Equity of voice achieved through participatory methods, facilitation, and structure of the meetings and process.

3.4.3 Limitations

Intervention development and evaluation guidance is consistent about basing intervention development on existing evidence.(18, 126, 137) The patient participation literature is vast, but there is a lack of theoretically informed and robustly evaluated interventions, partly due to moral arguments for participation.(3, 116) Boivin's intervention was a close fit with our aims to explore patient participation in prioritising service improvements.(101-103) Since the start of this project there have been additional limited interventions, including one promoting a participatory action research approach, but none have developed theory.(98-100) However, it is possible that there are successful interventions in other fields which could have influenced the design.

It was not possible to test the content, structure, and format of all intervention meetings during the development process. This was because the content of later meetings depended on the outcome of earlier meetings. Therefore, testing elements, such as the participatory voting, within the CRG was a pragmatic alternative. In addition, we moved from conceptualising the next stage as field testing, to ongoing iterative development and evaluation. Evidence based medicine has been criticised for a pipeline approach to complex interventions, with discrete packages of intervention development followed by evaluation, and then implementation.(105, 106) Hawkins et al described uncertainty about when to stop their participatory co-produced intervention development process.(198) However, Burns' definition of interventions as *interruptions* to systemic patterns, argues the exact detail of an intervention is less important than the aim.(143) Therefore, we ensured each intervention meeting had a clear aim. This also encourages flexibility which our findings, and the literature suggests, encourages ownership.(24, 134)

There are two main limitations related to the CRGs work on the intervention development. The first is that not all of the co-researchers were involved in the initial outline of the intervention developed during the 2014 study (Appendix 1). The need to apply for funding, and hence outline the project before commencement, and before establishing the CRG, is a recognised problem in academia.(127, 133) Co-researchers, both patients and staff, who did participate in discussions about the initial outline prior to the funding application were interested in the principle of using a prioritisation survey and forcing trade-offs. However, we did not discuss the detail of the method (see Chapter 4) until after the funding had been obtained. It was at this point that some, but not all, of the co-researchers became concerned about the method, but the study design could not be changed because this had been agreed with the funder. The second limitation is that the CRG did not include administrative and reception staff (including practice managers). We did not realise how influential this group are in terms of PPGs until the focus groups. We were unable to rectify this because as employees, this group have little agency over their work and were unable to commit to the CRG.

3.5 Conclusion

This chapter outlined the **development of our intervention to strengthen the role of patient participation in general practice service improvement**. This has focused on the partnership working component of the intervention. Specifically developing the content, structure and format of intervention meetings, and, from this, we developed a detailed intervention outline. Through the development process we used NPT to pre-empt implementation barriers and address these in the design. We have also extended the three theoretical constructs (credibility, legitimacy, and power) needed for meaningful patient participation.

4. Prioritisation survey design

This thesis is based on developing an intervention to strengthen patient participation in general practice service improvement. The intervention involves two participatory mechanisms. The first mechanism, *partnership working,* was described in Chapter 3. This chapter outlines the development of the second mechanism, *consultation,* using a prioritisation survey which is a discrete choice experiment (DCE). The aim was to design and test the content and format of a template prioritisation survey which could be easily adapted and used by PPGs. Participatory action research (PAR) recognises plurality of methods as a strength, as long as the methods can be justified and are context appropriate.(24, 108, 111) However, a key element of PAR is that the methods used are rigorous and scientifically sound.(19) Therefore it was important that the DCE template was developed with scientific rigour to ensure valid results.

The purpose of this chapter is to demonstrate the rigorous process of designing a DCE that can be adapted by individual general practices and PPGs, to investigate their patient populations' preferences for service improvements. Lancsar and Louviere describe six stages of designing the DCE, and this chapter will cover the first four stages (199):

- **conceptualising the choice process (4.3),**
- **defining the attributes and levels (4.4),**
- **creating experimental design (4.5),**
- **pilot testing (4.6)**,
- sampling,
- data collection.

The CRG (see Chapters 2-3 for details) were involved in conceptualising the choice process (including the overall survey design), defining the attributes and levels (including conducting a systematic review to identify attributes, and focus groups to get external feedback), and piloting the survey to test understanding, acceptability, and feasibility. I developed the experimental design and quantitative data analysis plan which are technical processes (section 4.5 and 4.6.1.3). Most literature implies that these stages form a linear process.(199) Therefore, I have chosen to present the design stages in sequence, with methods and results for each stage discussed in turn. However, in reality and in line with the PAR approach, the process was iterative and cyclical with data from the later stages informing earlier stages including the conceptualisation of the choice process. I will start by explaining the rationale for choosing a DCE for the prioritisation survey. The rationale for using a prioritisation survey is discussed in Section 2.7.

4.1 Rationale for choosing a discrete choice experiment for the prioritisation survey

A DCE is one method of eliciting stated preferences. Stated preference methods are based on economic theory of consumer behaviour and assume people are rational decision makers, making decisions to maximise their innate benefit.(185) They force people to weigh-up the costs and benefits and make choices and trade-offs recognising resources may be limited.(184, 185) This leads to a closer approximation of the relative 'value' people place on specific service characteristics or attributes.(176, 186) Stated preferences are preferences elicited by analysing data about the choices people make between two or more hypothetical alternatives.(178) This is in comparison with revealed preferences, which are based on observing the real life choices people make in the everyday world.(178) Stated preference methods are useful when it is difficult to observe real life choices (choices happen infrequently or in a private setting), or where a change is being considered but has yet to be implemented, and therefore choices cannot be observed (for example introducing a new service or making a change to an existing service).(178) For this latter reason, DCEs are commonly used in policy making to understand consumer or voter preferences before a change is implemented. However, it is important to recognise that stated preferences are based on the assumption that people will make the same choice in reality.(178) Therefore, stated preference instruments must be carefully designed so they resemble the everyday context in which the choices would likely be made.

Stated preference methods include a number of different methods: rating scales where attributes are assigned to a continuous scale based on desirability; ranking methods where attributes are ranked in order of preference; time-trade-off (TTO) methods where attributes are traded against time; some willingness to pay (WTP) methods where attributes are traded against monetary value; or DCEs in which respondents are forced to choose between discrete alternatives.(178, 184) However, rating scales and ranking do not involve trading off and therefore do not reflect real life choice behaviour.(184) TTO methods involve trading attributes, but only against time. TTO methods have a complex format and limit the number of attributes which can be compared.(200) Most WTP methods involve the generation of threshold willingness to pay values rather than trading attributes. Previous studies conducted in the UK, have experienced considerable problems with trading cost attributes because NHS care is free at the point of access, and people object to paying for health.(184, 201, 202)

Therefore, WTP methods do not reflect the reality of most choices in UK settings.(201) DCEs more closely resemble the complexity of everyday choices by asking participants to pick between alternatives comprised of multiple attributes.(176)

DCEs aim to investigate the impact of different attributes (characteristics) of a service, on the overall benefit or value (utility) an individual derives from a service.(184) This is achieved by comparing different service scenarios (alternatives), each with different levels of every attribute.(184, 185) Economic theory of consumer behaviour, ‘random utility theory’, suggests DCEs are the method that most closely represents how people make choices in reality: comparing different levels of different attributes that make up a service to derive overall utility (satisfaction).(184, 185) This utility cannot be directly observed because it has two components which describe it.(203) Firstly a systemic (explainable) component consisting of the different attributes and sociodemographic characteristics which affect an individuals’ choice.(203) Secondly a random (unexplainable) component which is comprised of all the unidentified factors which influence choices.(203) A strength of DCEs is that they acknowledge this random component, reflecting how real life decision making occurs.(203)

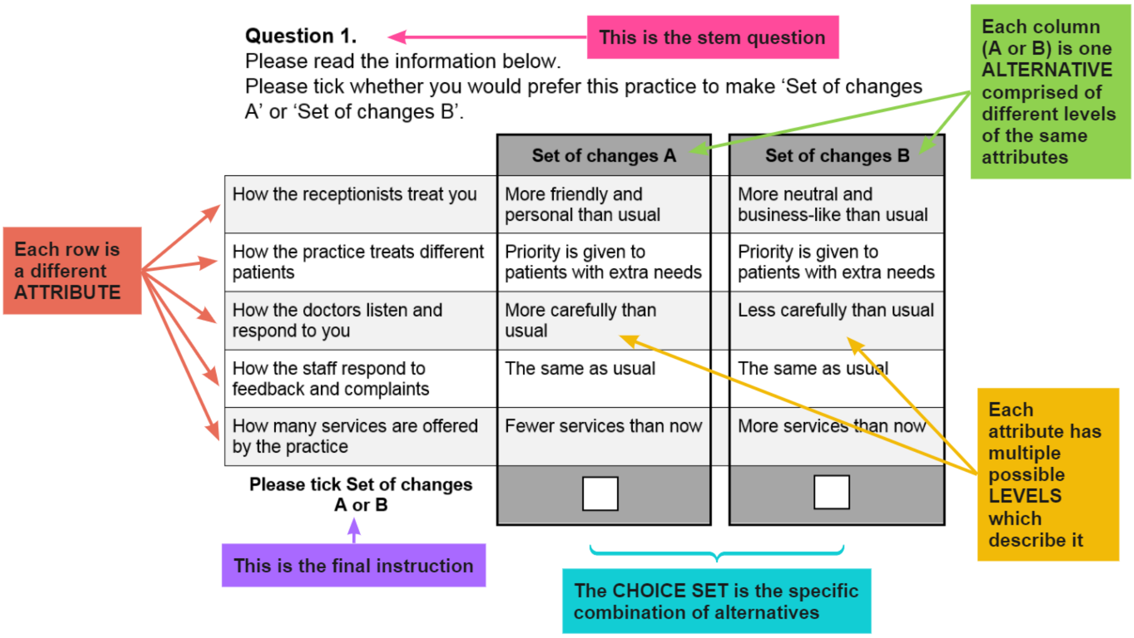
4.2 Overview of the components of a discrete choice experiment

DCE surveys typically comprise a number of different sections: an introduction which sets the context for the choice decision; a series of choice tasks; and a series of demographic and or service use questions which might explain an individuals’ choices.(176)

Choice tasks also include a number of features (Figure 4.1):

- The **attributes** are specific features or characteristics of a service.
- Each attribute has a range of **levels** which describe the attribute.
- The **alternatives** (A or B) are hypothetical options comprised of different levels of a number of constant attributes.
- The **choice set** is the specific combination of two (or more) alternatives.
- The choice task also includes a question stem or scenario and a final instruction.

Figure 4.1. The structure of a choice task



Question 1.
Please read the information below.
Please tick whether you would prefer this practice to make 'Set of changes A' or 'Set of changes B'.

	Set of changes A	Set of changes B
How the receptionists treat you	More friendly and personal than usual	More neutral and business-like than usual
How the practice treats different patients	Priority is given to patients with extra needs	Priority is given to patients with extra needs
How the doctors listen and respond to you	More carefully than usual	Less carefully than usual
How the staff respond to feedback and complaints	The same as usual	The same as usual
How many services are offered by the practice	Fewer services than now	More services than now
Please tick Set of changes A or B	☐	☐

4.3 Conceptualising the choice process

4.3.1 Framing this discrete choice experiment

The conceptualisation of this DCE differs in two major areas compared to most DCEs about general practice services identified in the systematic review below (Section 4.4.1). Firstly this DCE asks respondents about their preferences for *service change*, rather than just their preferences for *services*. Secondly the decision makers and potential target for change is the *individual general practice*, rather than regional or national policy makers designing a policy to be implemented across *multiple general practices.*

Asking respondents about their preference for change, not just their preference of general practice service attributes, is a subtle but important difference. An individuals' most preferred attribute might be length of appointment, however, they may also be happy with appointment length at their current practice, but really want to see changes in continuity of care. Therefore, one individual can have different preferences depending on whether they are asked what attribute is most important, or what attribute is their priority for improvement. Giving people the opportunity to state not just what they like, but what they want to change, potentially increases democratic validity of the instrument and agency of the individual.

DCEs need to realistically reflect available policy choices.(178) Therefore it is essential that attributes are relevant to the context of the general practice where the desired change will happen. Most DCE's in our review are conducted at a national level aiming to influence national policy decisions.(176, 178, 199) As discussed in Chapter 2, this project conceptualises general practitioners, practice managers, and their PPGs as the policy makers, and their individual general practice as the unit affected by the policy or service change. Despite there being a national English general practice contract, there is wide variation in how general practices deliver this contract, and this is heavily influenced by GP partners.(92, 93, 144, 179) Therefore, the priorities for improvement or change are likely to be different in one practice to another, change over time, and GPs have considerable power over decision making. As such, we aimed to design a DCE survey template that could be used flexibly, adapt to this variation, and influence individual general practice policy making.

For respondents to reveal their true preferences, and avoid responding strategically, they need to believe that the choices they make in the survey, will be implemented and have real impact.(178) Therefore, we developed a survey that could be individualised, linking it to each general practice by using their logo, framing the choice in relation to each individual practice, and distributing each survey via the practice. This individualisation may increase the belief by respondents that they can influence change.

4.3.2 Framing the choice task within the discrete choice experiment

Conceptualising the DCE includes framing the choice task within the DCE.(199) We aimed to keep the choice task as simple as possible, recognising patients completing the survey in a waiting room may be unwell or have little time. Therefore, we designed a DCE with two alternatives. Choice tasks can include more than two alternatives, but more options increase the complexity and may reduce response rates.(199) Choice tasks can also include opt-out and status quo options, allowing respondents to avoid making trade-offs.(199) This makes it easier for the respondent, and reflects the reality that people sometimes choose not to use any services over a less preferred service. However, in order to analyse the data, researchers must be able to describe what the opt-out or status quo option means for the respondent in terms of the attributes and levels in the existing general practice.(199) This can involve significant extra work mapping existing attributes and levels in each general practice, which would be incompatible with a survey template aiming to be used in different general practices. Alternatively, other surveys have asked respondents to complete a 'report card' on their perceived levels of attributes in their current general practice.(199) However, this increased the length of the survey and work for the respondent. Therefore, we did not include opt-out or status quo options.

4.4 Defining attributes and levels, and survey template

Discrete choice theory suggests that people choose between goods (such as a general practice) based on the package of features or attributes of goods (location, type of appointments available, knowledge of the doctors' communication skills), to maximise their innate benefit.(185, 204) Changes in the attributes can result in a discrete switch in preference from one good to another.(204) Therefore an attribute is a characteristic or feature of a good, in this case general practice, which may explain a preference for one general practice over another. Attributes have different levels which can be quantitative such as distance to the general practice (one, two, or five miles), or qualitative such as communication skills (good, indifferent, or bad).(199)

DCEs cannot include every attribute possible, however, they should include the important and relevant attributes.(93) The choice available to respondents depends on the attributes presented to them. Normally, policy makers and researchers decide what the important and relevant attributes are. This DCE frames PPG members and staff as the policy makers deciding what is important, relevant, and feasible to change in their general practice, before consulting the wider patient population. To ensure PPGs and staff pick valid attributes we systematically developed and tested common attributes and levels, to develop a list that they could choose from.

Attributes and levels are commonly developed from a combination of reviewing the existing literature and qualitative research with key stakeholders.(199) In this project, as has described in Chapters 2 and 3 (see Figure 2.2), the attributes and levels were identified through an iterative process of:

- reviewing the literature to identify common attributes (4.4.1),
- co-research group (CRG) deliberations to develop a list of attributes and survey template (4.4.2),
- focus groups with PPGs and staff to explore the collective understanding of attributes, levels and the survey template (4.4.3),
- pilot testing to check individual comprehension of the attributes and levels.(4.6)

The next sections will outline the process of designing the attributes and levels and survey template. Whereas Chapter 3 focused on what we learned from working together, this chapter focuses on the implications for the design of the attributes and survey.

4.4.1 Systematic review to identify common attributes

There have been previous systematic reviews of attributes of primary care (181) and healthcare delivery more generally.(205) However, at the start of this project there were no existing reviews of how attributes have been used in general practice stated preference studies. Therefore, we systematically searched the literature to find stated preference studies regarding the organisational attributes of general practice care. We aimed to explore how DCEs had been used previously, in what context, and using which attributes and levels.

4.4.1.1 Methods

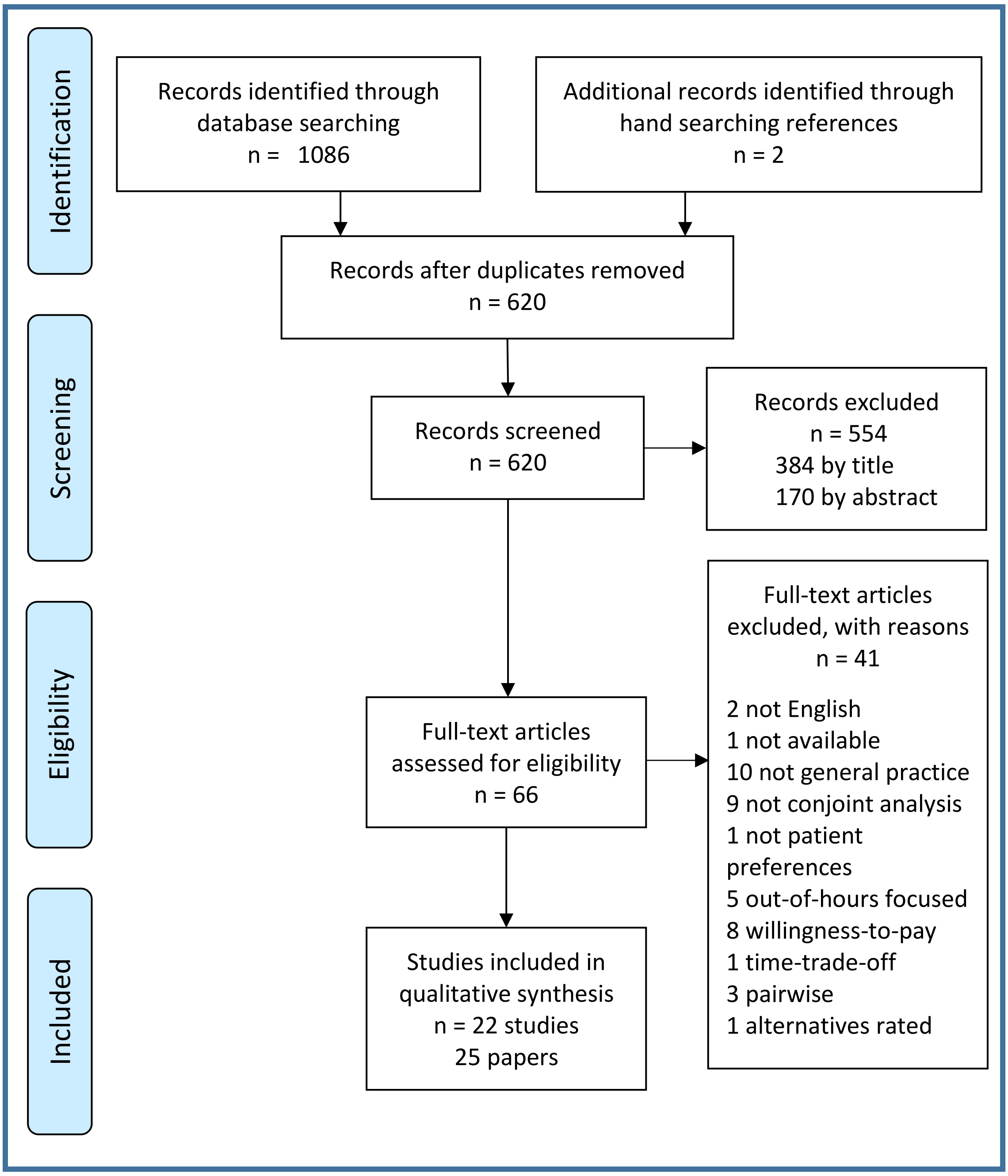
Search terms were developed based on previous systematic reviews of stated preference methods and primary care (Appendix 16). MEDLINE, EMBASE, HMIC, which cover the majority of primary care and health economics literature, were searched from 1980 to July 2016. The aim of this review was to identify the key studies in this area, accepting some smaller studies may be missed as they are published in the grey literature.(206) Detailed inclusion and exclusion criteria are available in Appendix 16. Non DCE stated preference methods were excluded for a variety of reasons discussed in section 4.1. In addition, pairwise studies were excluded as they force respondents to pick between two attributes at a time, which does not reflect complex decision making.(185, 207-209) No formal quality assessments were performed as we aimed to identify an exhaustive list of attributes to stimulate CRG discussion, regardless of whether they were used in high quality studies.

To reduce bias, one co-researcher also screened titles and abstracts. She influenced the search strategy by challenging my interchangeable use of the terms ‘primary care’ and ‘general practice’. We also agreed key delineation between DCEs conducted *about* general practice, and those conducted *within* general practice. A data extraction table was developed from the literature.(199, 210, 211)

4.4.1.2 Results

Twenty five papers were suitable for inclusion in the review, covering 22 studies using DCEs to explore preferences for general practice services. The PRISMA diagram (Figure 4.2) outlines the search results.

Figure 4.2. PRISMA diagram (based on Moher et al (212))



The 25 papers were published between 1998 and 2015, with an average of two papers per year between 2005 and 2015. The 22 studies include thirteen UK studies (201, 202, 213-225), six European studies (one pan-European (226)) (119, 226-230), two American studies (231-233), and one Australian study (234). Appendix 17 provides a detailed overview of the design of the 22 DCEs. In summary, the DCEs were administered by postal survey, handed out in general practice, administered by interview, or internet based surveys. The average response rate was 60% and mean sample size was 910 people (standard deviation 718). Forty different attributes were used in the 22 studies, with between three and eight attributes used per study (average 5.36). The wording of the attributes and levels varied widely. The attributes and levels are summarised in detail in Appendix 18. Sixteen attributes were used in more than one study (Table 4.1) and 24 were used in only one study. The most common attribute was waiting time for an appointment. This is a quantitative attribute with levels described in number of days.(176) Qualitative attributes include 'who you see' (levels: doctor or nurse) and 'shared decision making' (levels: the patient makes the decision, the doctor makes the decision, or there is a joint decision).(206) Waiting time for an appointment is used frequently as it can be used to provide a numerical value to compare other attributes (for example, number of days people are prepared to wait to see a doctor rather than a nurse).(214) The attributes used less frequently were often specific to a particular study, such as 'breadth of health review' used in a study focusing on preferences of patients with long term conditions.(218)

Table 4.1. Frequently used attributes of primary care

Attribute	**No. of studies**
Waiting time for appointment	17
Length of consultation	8
Opening hours	8
Who you see (which clinician role)	7
Shared decision making	7
Price	6
Quality of information given	6
Whether the clinician listens	5
Distance (time or km)	5
Relational continuity of care	5
Quality of clinicians explanation	4
Clinicians interpersonal manner	4
Waiting time in waiting room	3
Care model (single GP/team)	3
Telephone access	3
Clinician is interested in your ideas	2
A further 24 attributes only used in one DCE (Appendix 18)	

The 22 studies divided into those exploring preferences about the organisational structure of general practice, and those exploring preferences about consultations within general practice. Fifteen studies investigated patient preferences for specific regional or national policies, aimed at reforming the organisation of general practice. These policies included: urgent access centres (215, 231, 232), primary care teams (229, 230), greater patient choice (219, 226), efficient resource use (221, 227), diversifying the workforce (214, 217, 218, 231, 232), and improving access to GP appointments (216, 222, 233). One study compared patient, and doctors' perceptions of patient preferences for structural attributes of general practice.(119) Doctors did not know patients' preferences, and therefore should not represent patients in a decision making process. Six studies investigated patient preferences for consultations within general practice. Five of these were also influenced by policy objectives including: shared decision making (220, 223, 225), patient centred care (201, 202, 213), and improving access (224). One study explored the attributes of a consultation that would make a patient choose to change GP.(234) No studies examined resources within individual practices or compared individual practices. As all of these studies were designed for regional or national policy makers, GPs in a local general practice may struggle to use the results to make decisions about local service improvement.

To ensure the scenarios are realistic, good practice suggests attributes and levels are designed following a literature review and qualitative research, and then piloted to test comprehension.(199) However, only one study (four papers) undertook a systematic literature review of attributes of primary care (181, 201, 202, 213), and five studies (six papers) reported no literature review.(218, 221, 224, 231, 232, 234) Eight studies based the attributes on qualitative research, but there were limited details about the methods.(119, 214-216, 224, 230, 233, 234) Four studies based their design on other surveys (217, 218, 221) or randomised control trial data (219). Eight studies based the design on discussions with ‘experts’, often within their own team, and usually with very little detail about the experts.(215, 217, 218, 222, 224, 226, 227, 233). Only two of these papers reported involving patient experts.(222, 226) Eleven studies (13 papers) piloted their DCE to check comprehension.(119, 201, 202, 213, 214, 216, 219, 222, 224, 226, 229, 230, 233) The pilot of one UK study raised serious concerns about the use of a cost attribute.(201) The authors decided to keep the cost attribute as they wanted to be able to calculate WTP for a policy audience.(202)

4.4.1.3 Implications for the development of this DCE

The systematic review provided 40 attributes and levels to inform CRG discussions, and the design of the attributes, levels, and choice tasks. This included rationale for avoiding certain attributes such as cost. The systematic review clearly defines two gaps in the design of DCEs. The first gap is the lack of patient participation in the design of the DCEs. Only two studies clearly stated involving patient experts in the design process.(222, 226) Lack of patient participation in the design, and the comparatively strong influence of the policy agenda, may explain why attributes patients objected to were still included in DCEs.(201, 202) The second gap is the policy level at which the DCEs are designed to influence. None of the DCEs in the review had been used to influence individual general practice decisions about service improvement.

4.4.2 Co-research group (CRG) deliberations to develop a list of attributes and survey template

In comparison to the DCEs identified above, the attributes and levels for this DCE were developed by the CRG comprised of both patients and general practice staff.

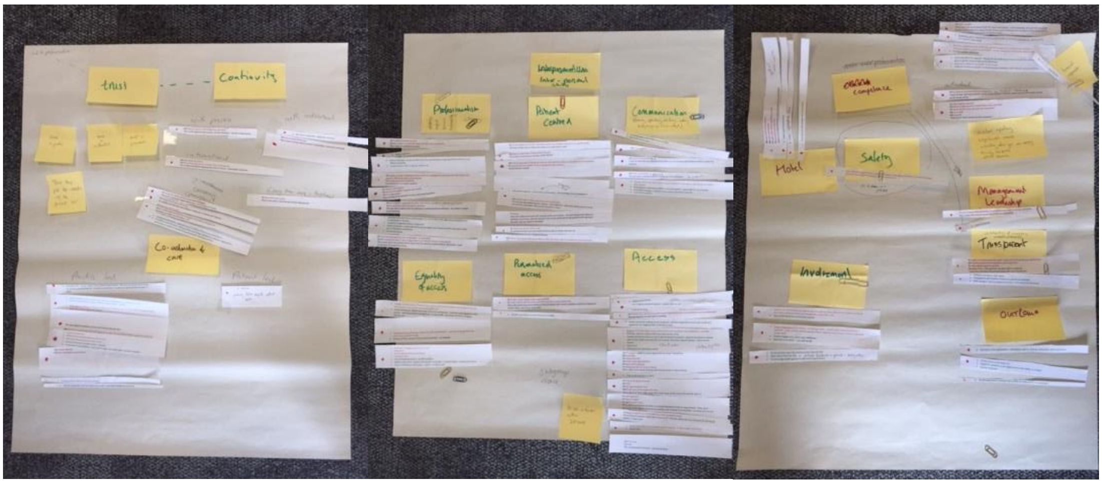
4.4.2.1 Developing and refining the list of attributes and levels

The CRG developed a comprehensive list of all possible attributes of general practice services over four deliberative meetings. Co-researchers used a participatory flexible brainstorm approach (see Chapter 2, section 2.5.2.2, Table 2.2) to generate attributes from their experience. Then added attributes identified in the systematic review above, and two existing attribute 'maps' developed from systematic reviews.(181, 205) These attributes were written on sticky notes or bits of paper (Figure 4.3).

Figure 4.3. Sticky note map of the co-research groups attributes of general practice

The co-researchers then thematically categorised attributes by physically moving them into different groups (Figure 4.4) using participatory charting (see Chapter 2, section 2.5.2.2, Table 2.2). This involved active discussion and sense checking. This process allowed refinement and clarification of the attributes, reducing overlap and dividing attributes with multiple meaning. The categories developed deductively from the previous literature, and inductively when existing categories were not clear or sufficient. The inductive categories included: 'engagement, openness and transparency', 'equity', 'being well-managed or quality of care', 'wellbeing', and 'how general practice supports wider community care'. This process produced 128 attributes, organised into 10 categories with sub-categories (Appendix 19). The CRG decided this process was exhaustive, and agreed saturation had been achieved in terms of important new attributes and managing the number of attributes.

Figure 4.4. Participatory charting of attributes into categories



The ten co-researchers then voted on their top ten attributes from the list of 128. This was a modified form of participatory voting (see Chapter 2, section 2.5.2.2, Table 2.2). Co-researchers picked their top ten attributes prior to the meeting, then shared their votes in the meeting, followed by a discussion. Ranking was not performed as co-researchers were overwhelmed with the number of attributes. Fifty attributes were chosen at least once, and these were taken forward to develop further.

The CRG then consulted two of my supervisors (a health economist (DM) and clinical professor of primary care (RF)) for expert feedback on the 50 attributes. RF removed attributes that he felt were an expected professional standard and therefore not amenable to change (for example *trusting the doctor to act in the patients' best interest*). DM removed attributes that related to 'outcomes', such as satisfaction or confidence, which he felt would be difficult to change. This reduced the list to 30 attributes. Levels were developed for all 30 attributes by the CRG drawing on the findings from the review. The attributes and levels were reviewed by an external company specialising in accessible language (Bradford Talking Media). These attributes and levels were then used in the focus groups and the pilot where further feedback and changes were incorporated (see below). Table 4.2 shows the 30 attributes and levels before and after the focus groups and pilot.

Table 4.2. Attributes and levels before and after the focus groups and pilot

No.	**Attributes prior to focus groups**		**Attributes after the pilot**	
	Attribute	**Levels**	**Attribute**	**Levels**
		Attribute category: Access to care		
1	Length of appointment	5 min; 10 min; 15 min; 20 min.	How long your appointment lasts	2 minutes shorter than usual; The same length as usual;

				5 minutes longer than usual; 10 minutes longer than usual.
2	Waiting time for a non-urgent appointment with any clinician	Same day (within 24 hours); Next day (within 48 hours); 5 days; 10 days.	How many days you wait to get an appointment	Longer than usual; The same as usual; Shorter than usual.
3	Waiting time for an urgent appointment with any clinician	4-6 hours Same day (within 24 hours); Next day (within 48 hours).	Removed	Removed
4	Communication method with doctors and nurses	Face to face only; Face to face and by telephone; Face to face and by email; Face to face and by video.	How you can talk to the doctors and nurses	Fewer options than now (face to face only); The same options as now (face to face and telephone); More options than now (current options and online).
5	Opening times	8am-6pm Monday to Friday only; 8am-6pm Monday to Friday, with some appointments earlier than 8am and/or after 6pm, only; 8am-6pm Monday to Friday, with some weekend appointments, only; 8am-6pm Monday to Friday, with some appointments earlier than 8am and/or after 6pm, and some weekend appointments.	When you can have an appointment	Fewer evening, morning, or weekend appointments; The same times as now; More evening, morning, or weekend appointments.
6	Who decides who has home visits	The receptionists; A doctor; Me or my carer.	How easy is it to get a home visit	More difficult than usual; The same as usual; Easier than usual.

7	Ease of making an appointment	Easy; Complicated.	How easy it is to book an appointment	More difficult than usual; The same as usual; Easier than usual.
Attribute category: How I am treated during the appointment – person centred care				
8	Communication style of the doctors and nurses	Friendly and personal; Neutral and professional.	How the doctors and nurses treat you	More neutral and business-like than usual; No change from usual; More friendly and personal than usual.
9	Listening skills of the doctors and nurses	They listen and respond to me; They do not listen or respond to me.	How well the doctors listen and pay attention to you	Less carefully than usual; No change from usual; More carefully than usual.
10	My involvement in decision making about my treatment	My doctor or nurse choose for me; My doctor or nurse choose considering my opinion; My doctor or nurse make a joint decision in partnership with me; I choose considering my doctor's or nurse's advice.	How involved you are in making choices about your care	Less involved than usual; No change from usual; More involved than usual.
11	Focus of my appointment	About my symptoms only; About my symptoms and how they are affecting me and my life.	How many problems you can discuss in your appointment	Only one problem per appointment; No change from usual; As many problems as you want.
12	Range of ways my health is supported	Medication only; Medication and referral to relevant community groups or activities that support my health.	How often community groups and lifestyle activities are suggested	Less often than now; No change from now; More often than now.
13	Advice about improving my lifestyle	Makes suggestions which fit my situation; Takes little account of my situation.	Removed	Removed

14	Support to manage my own health	Works with me on what I want to get from life; Seems to think everyone wants to get the same from life.	How you are supported to manage your own health	Less support and less personal advice than usual; No change from usual; More support and more personal advice than usual.
Attribute category: Continuity of care				
15	Medical records	The doctor or nurse has read my medical notes; The doctor or nurse has not read my medical notes.	How well your doctor or nurse knows your medical history	Less well than now; No change from now; Better than now.
16	Relationship with the doctor or nurse	I know them well, and they know me; I know them well, but they don't know me; I do not know them well.	How well your doctor or nurse knows you as a person	Less well than now; No change from now; Better than now.
17	Choice of doctor or nurse	I can always see who I want to see; I can sometimes see who I want to see; I can never see who I want to see.	How often you get your choice of doctor and nurse	Less often than now; No change from now; More often than now.
Attribute category: Co-ordination of care				
18	How the practice team work together	They talk to each other and work together; They do not talk to each other and work independently.	Removed	Removed
19	How the doctors and nurses work with the local community	They know about, and encourage me to use local support groups; They do not know about or encourage me to use local support groups.	How many services are offered by the practice	Fewer services than now; The same services as now; More services than now.
Attribute category: Equity				
20	Support for parts of my life that might affect my health	Housing or benefit requests are a top priority; Housing or benefit requests are done when they have time;	How much patients are charged for requests for letters of support	More than now; No change from now; Less than now.

		Housing or benefit requests are not supported.		
21	Interpretation services	I have to bring someone with me who can interpret; A telephone interpreter is provided; A face to face interpreter is provided; There are multilingual staff working at the practice who interpret.	How interpretation services are provided	No change from now (telephone interpreter); More options than now (face-to-face interpreter).
22	Treating patients according to need	All patients get the same length of appointment; Some patients get longer appointments if they have extra needs (eg young/old ect).	How the practice treats different groups of patients	All patients are treated the same; Priority is given to patients with more health problems.
Attribute category: Quality of care				
23	Attitude of the receptionists	Friendly and personal; Neutral and professional.	How the receptionists treat you	More neutral and business-like than usual; No change from usual; More friendly and personal than usual.
24	Confidentiality	I am sure my confidentiality is respected; I am not sure my confidentiality is respected.	How well the practice protects your privacy at reception	No change from now; Better than now.
25	The building	Warm, clean and tidy; Cold, dirty, and untidy.	How warm, clean, and tidy the environment is	Worse than now; The same as now; Better than now.
26	Availability of information about experience and expertise of staff	In the practice and online; Online only; In the practice only; No information anywhere.	Removed	Removed
27	How often my general practice	Daily; Weekly; Monthly.	How often you are asked about your	Less often than now; The same as now;

	meet to discuss quality of care		experience at the practice	More often than now.
28	Response to complaints and mistakes	Clear policies, open approach, and keen to learn from mistakes; No clear policies, closed approach, and not interested in learning from mistakes.	Removed	Removed
29	General practice attitude to change	Open to change to improve patient care; Reluctant to change to improve patient care;	Removed	Removed
30	How my general practice respond to feedback	Interested and try to act on it; Not interested and do not act on it.	How the staff respond to feedback and complaints	Slower to act than usual; The same as usual; Quicker to act than usual.

4.4.2.1 Developing the template survey

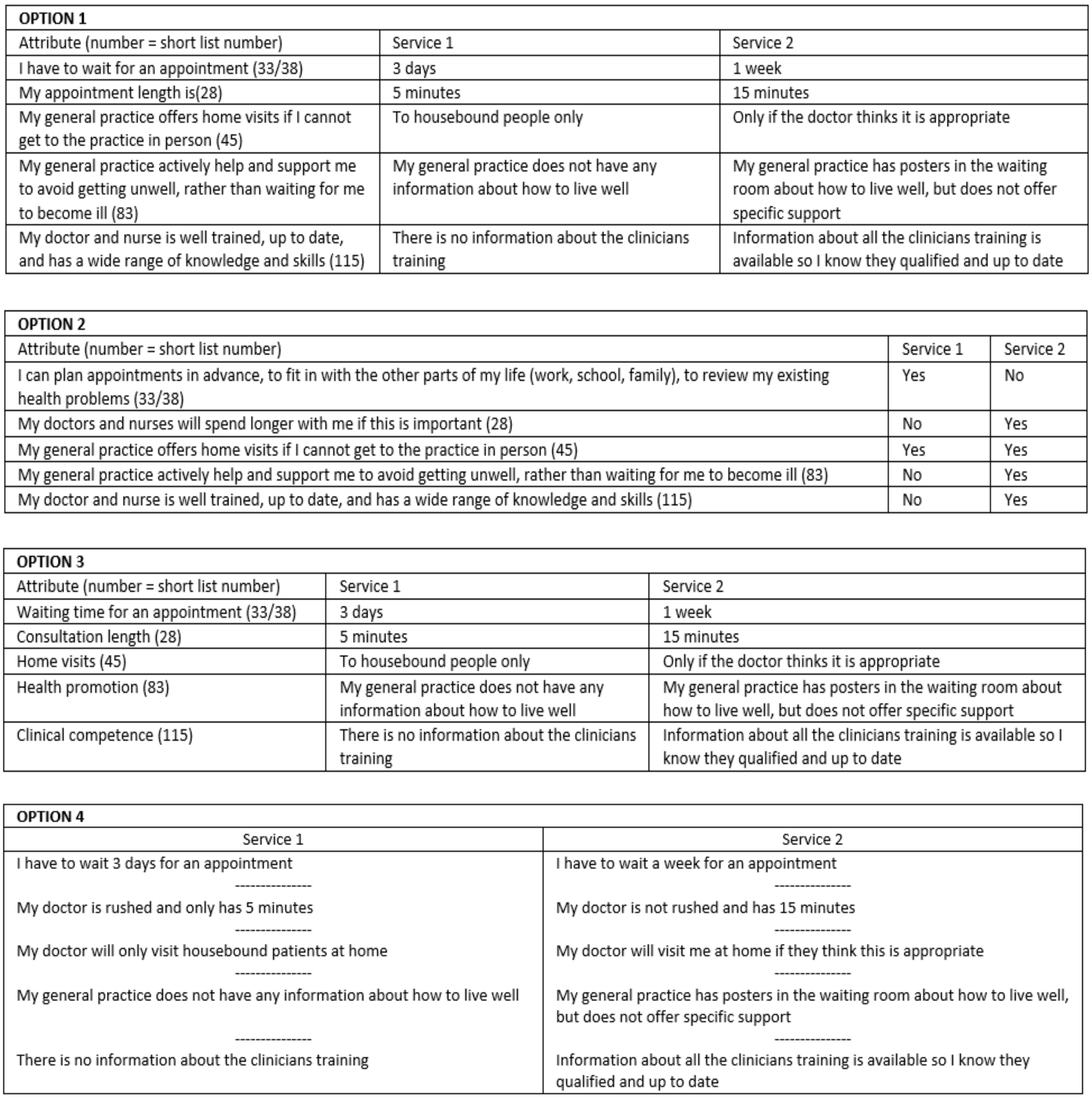
The CRG developed a prototype version of the adaptable piroritisation survey format and content over three deliberative meetings. This included desiging the:

- **Content and language of the survey introduction and demographic questions**.
  The co-researchers drafted the survey introduction, including instructions about completing the survey, and demographic questions. The content of the demographic questions was informed by the validated national General Practice Patient Survey. The emphasis was on keeping the survey short so it could be easily completed in the waiting room.
- **The format of the choice tasks**
  Four different styles of format of the choice tasks were identified from the systematic review (Figure 4.5). However, there was no evidence regarding the most effective format. The CRG reviewed the different styles and all voted for Option 3 as their preferred choice task style. We also agreed to use Option 4 on the ballot box as we needed a style with only two columns of text (one for each ballot box).
- **The survey mode of completion**
  The CRG reviewed a matrix of advantages and disadvantages of different modes of completion (Table 4.3). This matrix was based on common modes of completion identified in the systematic review and co-researchers' suggestions of modes they have experienced in other settings (electronic voting booths and supermarket charity

> ballot boxes). The CRG used participatory voting to agree which modes to take forward. The most preferred modes were online, and paper handed out in the waiting room, with assistance from the PPG. We also agreed to take forward the ballot box mode as an additional untried option.

Following these discussions draft versions of the paper and ballot box surveys were produced and refined by the CRG (the paper and online surveys were identical in content and style).

Figure 4.5. Styles of format of the choice tasks



OPTION 1

Attribute (number = short list number)	Service 1	Service 2
I have to wait for an appointment (33/38)	3 days	1 week
My appointment length is(28)	5 minutes	15 minutes
My general practice offers home visits if I cannot get to the practice in person (45)	To housebound people only	Only if the doctor thinks it is appropriate
My general practice actively help and support me to avoid getting unwell, rather than waiting for me to become ill (83)	My general practice does not have any information about how to live well	My general practice has posters in the waiting room about how to live well, but does not offer specific support
My doctor and nurse is well trained, up to date, and has a wide range of knowledge and skills (115)	There is no information about the clinicians training	Information about all the clinicians training is available so I know they qualified and up to date

OPTION 2

Attribute (number = short list number)	Service 1	Service 2
I can plan appointments in advance, to fit in with the other parts of my life (work, school, family), to review my existing health problems (33/38)	Yes	No
My doctors and nurses will spend longer with me if this is important (28)	No	Yes
My general practice offers home visits if I cannot get to the practice in person (45)	Yes	Yes
My general practice actively help and support me to avoid getting unwell, rather than waiting for me to become ill (83)	No	Yes
My doctor and nurse is well trained, up to date, and has a wide range of knowledge and skills (115)	No	Yes

OPTION 3

Attribute (number = short list number)	Service 1	Service 2
Waiting time for an appointment (33/38)	3 days	1 week
Consultation length (28)	5 minutes	15 minutes
Home visits (45)	To housebound people only	Only if the doctor thinks it is appropriate
Health promotion (83)	My general practice does not have any information about how to live well	My general practice has posters in the waiting room about how to live well, but does not offer specific support
Clinical competence (115)	There is no information about the clinicians training	Information about all the clinicians training is available so I know they qualified and up to date

OPTION 4

Service 1	Service 2
I have to wait 3 days for an appointment --------------- My doctor is rushed and only has 5 minutes --------------- My doctor will only visit housebound patients at home --------------- My general practice does not have any information about how to live well --------------- There is no information about the clinicians training	I have to wait a week for an appointment --------------- My doctor is not rushed and has 15 minutes --------------- My doctor will visit me at home if they think this is appropriate --------------- My general practice has posters in the waiting room about how to live well, but does not offer specific support --------------- Information about all the clinicians training is available so I know they qualified and up to date

Table 4.3. Matrix of the characteristics of different modes of survey completion

Format type	No. tasks	No. other questions	Sample/ reach	Response rate	PPG involvement	Practice resources	Respondent work load	Summary and appraisal
Online	High Flexible	High Flexible	Very High – random – how to target	Unknown depends on targeting	Low	Low	High if long No support	High volume of data with minimal effort. Depends on how the survey link is distributed. If on a website risk of non-practice patients completing it
Postal	High Flexible	High Flexible	High – targeted	Known – low	Very low	High – patient data and cost and time of posting	High if long and have to send it back No support	High volume of data. Could target specific groups. Address is confidential info so practice would have to post them. Postal costs high. Low response rate.
Paper handed out	Med	Medium	Medium – depends on availability	Medium – Needs promoting	Potentially high	Medium – depends on who is required to promote it	Medium depends on length No support	Medium volume of data. Handed to people coming into surgery. PPG could do this. Limited to those who come to practice – although could be handed out in other settings
Interview assisted	Medium	Medium /low – confidentiality	Low targeted	High	Very High (assuming they are doing the interview)	Low – assuming they trust PPG to do interviews	High – but supported e.g. low literacy	Assuming PPG do the interviews: would require training. Could ask lots of choice tasks, but minimal confidential info. Could be very targeted or waiting room based. Issues about sampling.
Voting booths	Low	Low	Medium – depends on availability	Unknown	Medium/high encourage pts and update booths	Physical space in waiting room	Low as short Potentially fun – novelty value high	Low volume of data and physically limited by the voting boxes so only in surgery. Very easy for respondents (only one question). PPG could have a role in promoting it.
Electronic delivery	Low	Low	Medium – depends on availability	Unknown	Low	Upfront cost of technology	Low as short Potentially fun – high novelty value	Low volume of data. Electronic device high cost and immobile. Very easy for respondents. Little work for PPG or practice. Issues around ownership of data.

4.4.3 Focus groups to explore the understanding of attributes, levels, and the survey

External qualitative stakeholder feedback is recommended during the attribute and level development process.(199) Therefore, the CRG conducted focus groups with existing PPGs who would be the users of the attributes and survey. The focus group methods are described in detail in Chapter 3, section 3.2.1.2. The findings reported below outline the feedback regarding the attributes and survey, and the resulting changes to the DCE. Changes were made iteratively after each of the six focus group based on the feedback.

4.3.2.1 Focus group findings

The first three focus groups reviewed all 30 attributes, but were clearly overwhelmed, and fed back that 30 was too many. Therefore, after the third focus group the CRG reduced the list to 23 attributes by changing, merging, or removing attributes based on focus group feedback (Table 4.4).

Table 4.4. Summary of changes to attributes made after focus groups 1-3.

Attribute	**Explanation of change, removal, or merge**
Waiting time for an urgent appointment with any clinician	Removed as unacceptable to wait for an urgent issue and poor differentiation between urgent and non-urgent appointments
Response to feedback	Merged as overlap causing confusion: “How do the staff respond to feedback and complaints”.
Attitude to change	
Response to complaints and mistakes	
Availability of information about the experience and expertise of staff	Removed as it was considered a basic standard of care.
How the practice team work together to provide my care	Removed as patients rarely see team work in action and did not think it was important to their care.
Range of ways my health is supported	Merged as overlap causing confusion: “How you are supported to manage your own health”.
Advice about improving my lifestyle	
Managing my own health	
Focus of my appointment	Changed to incorporate new attribute: “How many problems you can discuss in your appointment”.

In Focus Group 4 there was feedback about the wording of the levels which had a significant impact on their design. This was discussed with the CRG which raised two issues:

- The public have very little detailed knowledge about how general practice work is organised. Participants did not know about attributes they did not have direct experience of (such as paying for letters of support, or using interpreters). But they also did not have full information about attributes that they do have experience of, such as whether appointments are supposed to last 10 or 15 minutes. Therefore, despite designing specific and discrete levels, these were interpreted abstractly.

- Levels of attributes vary significantly between different general practices, and the degree of variation makes designing consistent levels almost impossible. In Focus Group 4 the current waiting time for an appointment was four weeks, but the maximum level was 10 days. Therefore, in this practice, a 10-day level would represent a preference for shorter waiting times. This meant the levels for each attribute would potentially need to be checked and redesigned in every practice.

As a result, we redesigned all the attributes to have relative rather than absolute levels. For example, the levels for appointment length became ‘shorter’, ‘the same’, or ‘longer than now’. This decision was based on the following rationale:

- Relative levels do not require existing knowledge of the organisation of the general practice and can rely on subjective opinions.
- Relative levels will not need to be redesigned for each general practice.
- Relative levels are in keeping with the conceptualisation of the DCE around preferences for change, and not just preferences. Patients’ preferences for general practice may be idealised. Patients’ preferences for change will be relative and depend on the service they have experienced.
- This DCE conceptualises individual patients as capable of making decisions based on their experiential knowledge. Therefore, they should not need detailed knowledge of how general practice is organised in order to complete the survey.

Focus groups 5 and 6 reviewed the list of 23 attributes with the relative levels. In both groups there was less discussion about the levels and what the current practice characteristics were, with more focus on preferences. In both focus groups, four attributes were still poorly understood. These were subsequently modified by the CRG and one attribute was reintroduced (Table 4.5).

Table 4.5. Summary of changes to attributes made after focus groups 4-6.

Attribute	Explanation of change or reintroduction
How many patients can have home visits	Changed to reflect patients’ experience of asking for a visit, rather than how many people could have a home visit: “How easy is it to get a home visit”
How the practice protects and uses your personal information	Changed to remove reference to information which is a legal requirement and not changeable: “How well the practice protects your privacy”
How long your doctor or nurse spends reading your medical notes	Changed as staff felt patients wouldn’t know this, and the patients didn’t know this and didn’t think the length of time was the issue: “How well your doctor or nurse knows your medical history”
Range of ways my health is supported	Reintroduced because despite being merged due to overlap previously, it kept coming up as a separate topic: “How often community groups and lifestyle activities are suggested”

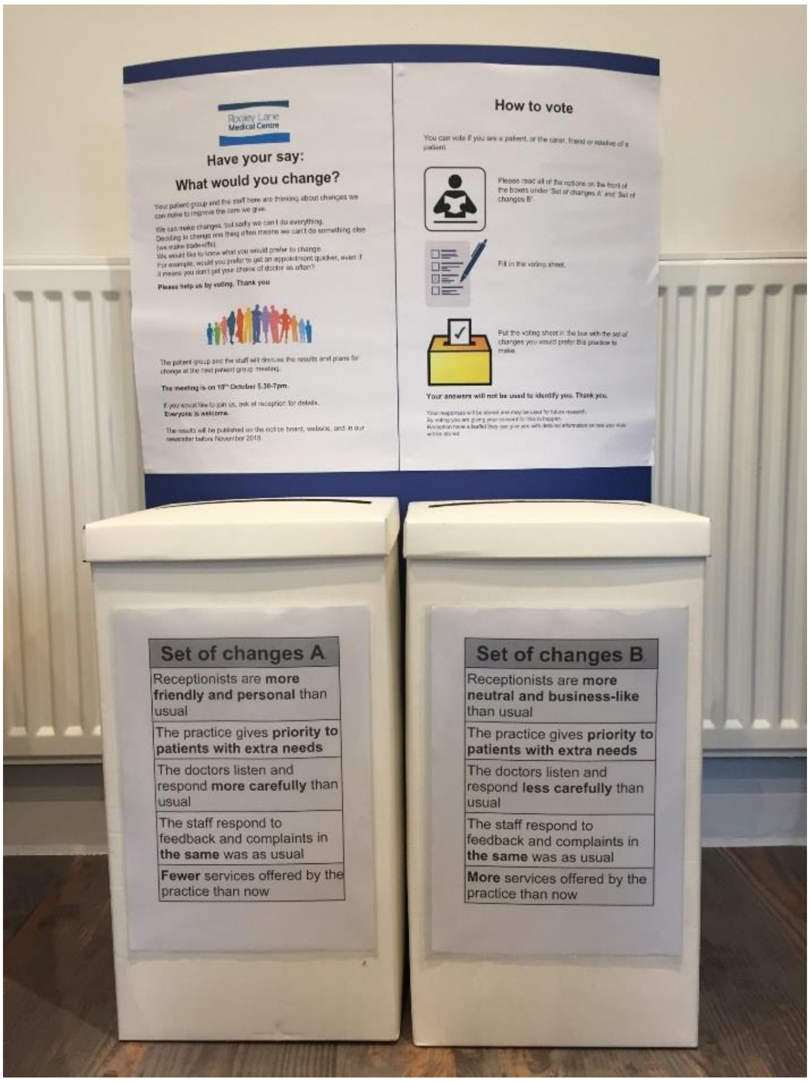
Feedback on the survey content helped to improve the language of the survey. The biggest changes were the addition of two further demographic questions. One patient in focus group 3 suggested a question regarding whether respondents worked, arguing this would affect their ability to access appointments in working hours. There were also persistent concerns about the complexity of the survey and whether patients would complete it. Therefore, to evaluate whether people with low literacy were being excluded, we added a question about education level.

Bradford Talking Media then reviewed our content for a final time. We produced prototype versions of the 24 attributes, the paper survey, and the ballot box for the pilot. A software company (ACCENT) produced the online version of the survey, based on the paper survey. All modes of survey completion included:

- Introduction and instructions,
- A number of choice tasks,
- Demographic questions,
- A free text response section,
- An advertisement for the PPG.

For the ballot box survey this material was physically displayed on a poster and the front of the boxes (Figure 4.6), see Appendix 21 for the paper version of the pilot survey.

Figure 4.6. Pilot prototype of ballot box survey



4.5 Experimental design for the pilot

The experimental design of a DCE describes how combinations of attribute levels and alternatives in choice tasks are derived.(199) A DCE with five attributes (A), each with three levels (L), has 243 different possible combinations of choice tasks (L^A).(93) This is called a 'full factorial' design. This is too many for one person to complete, therefore the experimental design is a sample from all possible combinations which allows an estimation of the main effects of the choice model.(203) In this project we aimed to keep the number of choice tasks per respondent low, to reduce their cognitive burden. Blocking (grouping) different choice tasks into different survey versions, then randomly assigning these to different respondents, increases the number of choice task combinations without increasing individual cognitive load.(204) The average number of choice tasks per study in the systematic review above was 5. The three modes of completion of the survey impacted on the number of choice tasks (Table 4.6).

Table 4.6. Number of choice tasks by mode of completion and distribution

Mode of completion	Distribution	Choice tasks per person
Online	Weblink sent via Text message and completed at respondents convenience. Available on handheld tablet in the waiting room.	5
Paper	Distributed by the PPG in the waiting room so needs to be short.	3
Ballot box	Physical voting in the practice limited to one choice task.	1

Once we decided on the number of attributes, levels, choice tasks and blocks, I used Ngene software to produce a d-efficient experimental design**.**(199, 210) Efficiency in experimental designs relates to the precision with which the choice model can be estimated.(199) More efficient models produce more precise estimates for any given sample size and maximise the potential for trade-offs. The d-efficient design was checked to ensure even distribution of levels (all levels appear a relatively equal number of times throughout the design) and to avoid dominated choice tasks. Dominated choice tasks are where one alternative is clearly better than the other.(235) These are often easier choices with less requirement to trade-off. The most efficient and useful data is found in choice tasks where respondents have to make difficult decisions and trade off different attributes revealing their preferences.

Across the pilot we needed to test all three modes of completion, and all 24 attributes and levels. Therefore, each respondent completed all three survey modes. The attributes were split into different versions of the survey so that we received feedback on all attributes and levels. The five most frequently picked attributes from the focus groups were tested in the online survey (Table 4.7). These were attributes likely to be picked again and we wanted to maximise their feedback. The remaining 19 attributes were tested in different versions of the paper and ballot box surveys.

Table 4.7. The five most common attributes chosen in the focus groups

Attribute	**Votes * 5 FGs**
5. When you can have an appointment	3
7. How easy it is to make an appointment	5
2. How long it takes to get an appointment	4
12. How often community groups and lifestyle activities are suggested	3
17. How often you get your choice of doctor or nurse	3

To ensure the quality of a DCE it is good practice to add validity and reliability tests to a DCE. Janssen et al identified 24 different tests across four domains.(235) Table 4.8 summarises how I addressed measurement validity and reliability.(235) More tests could have been included, however, most would have required longer survey formats increasing the cognitive load and complexity of the survey. The choice of tests reflects a balance between the need for a practical survey appropriate for routine practice, and ensuring scientific quality of the survey.

Table 4.8. DCE validity and reliability tests based on Janssen et al.(235)

Test	**Use in this project**
Measurement validity	
Face/content validity: Does the choice task contain important attributes? Are the results consistent with a priori preference expectations?	**The attributes were developed with reference to the literature and expertise of the CRG.**
Convergent validity: Are the results consistent with other studies of the same issue	Adding another preference elicitation method (such as best-worst scaling) to the survey would increase the length and cognitive load, as would conducting further surveys. **However, comparison is possible between our results to those within the systematic review, and to the General Practice Patient Satisfaction survey**
External validity: Do the results accurately predict preferences	The CRG considered collecting revealed preference data. However, it was beyond the scope of this project.
Measurement reliability	
Test-retest: Is the response the same when the instrument is administered twice	**In the pilot, one choice task was repeated in the paper and ballot box surveys. The results were compared to see if choices were consistent.**
Version consistency: Do different survey versions produce consistent preference estimates	Due to the limited number of choice tasks, a fixed choice task across all survey versions would lose too much data. Future work could explore this if the practice samples are large.
Holdout prediction: Can the survey predict choices outside the choice model	This involves two stages of analysis: initial analysis on a sub sample to produce a model, followed by testing the model on the remaining data. It requires a large sample which we did not anticipate.
Choice validity	
Monotonicity: Do respondents choose 'worse' profiles over 'better' profiles	**The online pilot survey included dominated choice tasks** (those with clearly 'better' and 'worse' profiles of levels)**.**
Compensatory choices: Do participants trade between all attributes of choice profiles	**The interviews explored whether respondents were choosing by focusing on specific attributes (dominance) or ignoring others (non attendance).**
Task non attendance: Do participants pay attention to the choice tasks	**The pilot analysed whether participants always chose A over B (or vice versa).**
Choice reliability	

Transitivity: Do participants make choices that have consistent logic (if they prefer A over B, and B over C, then they should prefer A over C)	The priority was to test all attributes and levels. This would add another level of complexity.
Sen's consistency: Do respondents make choices consistently even when more (expansion) choices or fewer (contraction) choices are offered	This would mean adding more, different choice tasks to the survey (some with more alternatives) and repetition. This would increase the length and complexity of the survey.
Level recoding: Do respondents make choices based on the absolute value of numeric attributes	The only attribute with numeric levels was length of appointment. **The difference between the numeric levels was not equal.** But we did not have enough data to analyse this in the pilot.

4.6 Piloting the prioritisation survey

Piloting is recommended in the design of all DCEs.(199) Piloting is usually conducted for two broad reasons.(204) Firstly, to test the understanding and appropriateness of the DCE, specifically the attributes and levels, choice contexts, task complexity, timing and length of the experiment, and sampling strategy. Secondly, piloting is often used to check the experimental design to ensure there is appropriate coverage of attributes and levels and that responses are valid and in the expected direction (e.g. longer appointments preferred to shorter ones).(185, 199) In the above review, piloting was also often used to generate preliminary data to inform the analysis of the final DCE.

4.6.1 Pilot study methods

In early DCE designs, piloting was often limited to quantitative methods. However, more recent designs have involved the use of qualitative methods, specifically 'think aloud' interviews.(191, 201, 204, 236) These are interviews where the respondent is encouraged to "say what you are thinking" whilst they complete the survey.(191, 236) This produces data about how and why people answer survey questions. This enables in depth understanding of their interpretation of the questions they are being asked in the survey. At the end of the interview the respondent is also asked for their overall feedback about their experience of completing the survey. 'Think aloud' interviews are ideally suited to testing whether the attributes, levels, and choice context are understood as anticipated.(201) Therefore, we included think aloud interviews in this research (also see Chapter 3). One co-researcher attended all the interviews with me. He helped organise the survey versions, and timed the surveys. We exchanged observations after each person had completed the survey and I wrote reflective field notes.

Piloting this DCE was complicated by the need to test all 24 attributes, three modes of completion, and not knowing the final combination of attributes, as these would be decided by the intervention practices. Therefore, the pilot aimed to:

- Assess the respondent burden of the three modes of completion including length, cognitive burden, and literacy.
- Explore respondents understanding of the attributes, levels, and choice process.
- Test the experimental design, quality and validity, prepare an analysis plan, and check whether a small sample could provide valid results.

Not knowing the final combination of attributes meant the pilot was unable to generate preliminary data to inform the analysis of the final DCEs.

4.6.1.1 Pilot sampling and recruitment

The pilot population should be similar to the final survey population.(199) In England everyone is entitled to register with a general practice, therefore, the final survey population is the general public. In the final survey respondents will be recruited in the waiting room and via the general practice. This was not appropriate for the pilot, as attributes would not have been chosen by the PPG. Therefore, we worked with a local branch of Healthwatch (see Chapter 1) who recruited respondents from their register of volunteers and network of community groups. We aimed for a convenience sample with a maximum variation of age, gender, ethnicity, and literacy, to reflect a diverse general public.(104) Thirty responses are sufficient to pilot a DCE with 15 'think aloud' interviews.(201) The Healthwatch volunteer coordinator shared the participant information sheet with respondents in advance (Appendix 11). Respondents were paid £10 for completing the survey, and £30 for completing the survey as part of a 'think aloud' interview. Informed consent was taken prior to participation (Appendix 12). See Appendix 2 for ethical approval.

4.6.1.2 Pilot data collection

When completing the survey, respondents were asked to think about the last time they attended their general practice. All respondents completed all three modes of the survey, but the order was varied between respondents. All surveys were timed. Respondents completing the 'think aloud' interview were given a warm up task to familiarise them with thinking out loud. Interviews were audio-recorded and transcribed.

4.6.1.3 Pilot data analysis

The 'think aloud' interviews were analysed using inductive thematic analysis highlighting potential problems regarding how the survey questions were understood and answered.(194,

201) The CRG reviewed summaries of descriptive themes and discussed these in a focused analysis meeting where we agreed final changes to attributes, levels, and the survey content and format (see Chapter 3 Section 3.2.2 for more detail). The experimental design was tested by analysing the quality and validity tests. This included understanding how and why respondents made choices and looking for dominance and non-attendance of attributes.(235) The online survey data was analysed quantitatively using conditional logistic regression in STATA to test the analysis plan and sample size. A detailed description of the analysis is described in detail in Chapter 5. As all the respondents were registered at different general practices, the quantitative results represent the combination of different individuals' preferences for change in different general practices. Therefore, meaningful interpretation regarding the preferences of the pilot respondents is not possible.

4.6.2 Results of the pilot study

4.6.2.1 Survey length, cognitive burden, and literacy

Demographic details of the pilot survey responders are reported in Table 4.9. The average time to complete the survey was: 5.45 minutes online (5 choice tasks), 5.32 minutes paper (3 choice tasks), and 2.84 minutes ballot box (one choice task). Observations suggest the main cognitive load was the initial process of understanding the survey and choice task process. Therefore, respondents sped up as they completed repeated choice tasks. The most preferred mode of completion was the online version, but most respondents felt a combination of modes should be available.

Table 4.9. Demographic details of pilot survey responders

Median age:		40 (min 17, max 88)
Gender:	Female Male	25 (83%) 5 (17%)
Ethnicity:	White Asian Black Other	20 (67%) 6 (20%) 3 (10%) 1 (3%)
Educational level:	University College School	16 (53%) 9 (30%) 5 (17%)
Existing long term conditions:	Yes No Don't know	11 (37%) 18 (60%) 1 (3%)

Respondents did not like being asked to give their educational status. However, many expressed concerns that the language and design of the choice tasks would exclude people with lower literacy. Observations suggested people with lower educational attainment criticised the survey less and completed it more quickly. Veldwijk et al found that participants with lower education attainment were more likely to make choice task decisions based on fewer attributes and less trading off.(237) This suggests people with lower literacy may try to simplify the task by looking for dominant attributes, thus speeding up the process. Therefore, we retained the question about educational attainment, despite respondents' dislike of it.

4.6.2.2 Respondent understanding of the attributes, levels, and choice process.

The majority of attributes were easily understood or required minor wording changes to make them clearer. However, there were some attributes which were not understood or dominated decision making.

Most respondents did not understand the *'quality of care'* attribute. The concept appeared abstract, or not something patients should try and influence. Therefore, this attribute was changed to *'how often you are asked about your experience of the practice'*. This is a proxy for quality of care and something tangible that patients have experience of.

The following attributes dominated decision making: *'how well the doctor listens'*, *'how you are supported to manage your own health*', *'how well the doctor knows you as a person*', *'interpretation services*', and '*how well the practice protects your privacy'*. For each of these attributes respondents passionately disagreed with the *'less well'* level. Usually, respondents did not like the idea of these attributes being worse, but they could imagine how they might be worse, if for example the doctor was rushed. However, a number of respondents strongly objected on ethical grounds to interpretation services or privacy being worse. Therefore, the *'less well'* level was removed from these two attributes.

One attribute, *'community groups and lifestyle activities*', was consistently ignored by respondents. This is referred to as a non-attending attribute. A few respondents did not understand the concept. However, many genuinely did not value it, some saying they knew this advice already. It is worth noting this attribute was frequently chosen as a priority by PPGs, but not seen as a priority by the general public.

Three attributes, '*evening and weekend appointments'*, *'ease of making an appointment*', and *'waiting time for appointments*', appeared to interact. Respondents suggested that logically if there are more evening and weekend appointments, then it would be easier to get an appointment, and they would have to wait less long. This appeared to be based on two assumptions. Firstly, if there are more evening and weekend appointments, there are more appointments overall. Secondly, ease of making an appointment was equated with the *outcome* of getting an appointment, not the *process* of booking an appointment. Therefore the wording was changed to *'how easy it is to book an appointment'*. In addition, we changed *'how long it takes to get an appointment'* to *'how many days you wait to get an appointment'*. Attribute interactions and ordering effects will need to be taken into account during field testing.

Table 4.10 outlines other changes made to the survey formats to make them more engaging.

Table 4.10. Alterations to the survey format as a result of the pilot

Survey format	Alterations as a result of interviews
Online	No changes.
Paper	Original four page survey spread out over 6 pages to provide more white space.
Ballot box	Poster instructions redesigned with bigger font size and picture instructions.

4.5.2.3 Reliability and validity tests

The online survey included a choice task where one alternative (A or B) dominated (was clearly better).(235) This was always selected, suggesting respondents were reading the choice tasks and making choices, rather than picking A or B randomly. However, one respondent demonstrated task non-attendance by picking all A's on the paper version and another respondent admitted she just picked randomly.

To check test-retest reliability, one choice task was repeated.(235) The first choice task on the paper survey and the last attempt of the ballot box were the same. Nine out of the 30 (30%) respondents did not make the same choice in the repeated choice task. For seven of these participants, the paper survey, and hence the repeated choice task, was the first choice task they completed. It is therefore possible that they did not understand the choice task process at first and this is why they changed their choice on the retest. However, it is also possible that the ballot box survey is presented so differently that this affects respondents' choice, or that the survey is not understood or reliable.

4.5.2.4 Quantitative analysis

Thirty respondents completed all five choice tasks in the online survey. This equated to 150 choices and 300 data points. This provided enough data to produce a conditional logit regression model and statistically significant results. Therefore, for practices to undertake this survey in the future they would need at least 30 online survey responses, or 50 paper responses (each response includes three choice tasks), or 150 ballot box responses (each response is one choice task).

As mentioned above, interpreting the pilot data is impossible as respondents were from different practices. However, all results were in the expected direction (more prioritised over less), (185, 199) and *‘Community and lifestyle groups’* were the least preferred attribute which was consistent with the interview findings suggesting indifference.

The pilot also raised an important issue about the coverage and distribution of levels in the experimental design.(185, 199) The experimental design distributed the levels so that the *‘same as usual’* level was always compared with the *‘same as usual’* level. This resulted in effectively removing this level and only ever asking respondents to pick between *‘more’* or *‘less’* of each attribute. This was addressed in the final experimental designs.

4.5.3 Summary of the pilot study

The pilot provided an opportunity to test: the comprehension of the attributes and levels and the three modes of the survey, the experimental design, and the validity and reliability of the DCE. As a result, we made significant changes to the survey, and produced a final list of attributes (Table 4.2). I developed an analysis plan and identified problems with the experimental design which were rectified before field testing. We were also able to provide practices with an indicative sample size. As some significant changes were made, it could be argued another iteration of testing would be desirable. However, ideally, this would be with the final attributes and include tests for attribute interactions. Therefore, the CRG agreed to progress to field testing, but keep an open mind about ongoing survey iterations between intervention practices.

4.6 Summary

This chapter described a systematic approach to developing a template prioritisation survey which can be adapted by PPGs and practices and then used as a mechanism for consulting the wider patient population about their priorities for service improvement. The survey is a DCE, which is a stated preference method most closely representing how people make choices in reality.(176, 203) Together with the CRG, we followed the first four stages of the systematic approach to designing DCEs outlined by Lancsar and Louviere.(199) This involved:

- conceptualising the choice process,
- defining the attributes and levels,
- creating experimental design,
- pilot testing.

The conceptualisation of the choice process was different to other DCEs in our systematic review for two reasons. Firstly, it asks respondents about their preferences for service improvement, rather than services. Secondly, it framed the policy decision at the level of one general practice, with the PPG and staff being the policy makers. However, this resulted in two significant challenges related to ensuring the prioritisation survey was adaptable and flexible. The first challenge was producing and testing a range of attributes and levels that would realistically represent the wide variety of general practice contexts. The second challenge was producing a template survey that could be easily adapted to the local general practice and include a range of modes of completion for the PPGs and staff to choose from. At the end of the design process we had a list of 24 attributes and their corresponding relative levels, and template versions of three modes of survey completion (Appendix 20-24).

Good practice in the design of attributes and levels includes involving stakeholders, conducting literature reviews, and qualitative research.(199) We followed all these processes, and unlike the majority of the DCEs in our systematic review we included patient expert co-researchers in the design process. This was an iterative and cyclical process of developing an exhaustive list of attributes and then refining and shortening the list based on feedback. Finally, we tested comprehension of the attributes and levels in a pilot survey. It was not possible to test all 24 attributes in all three modes of survey completion. Therefore, we made pragmatic decisions to focus testing on the attributes most commonly picked in the focus groups. Our overall approach means that the list of attributes has considerable content validity.(235)

Piloting the survey enabled testing of the experimental design, the validity and reliability of the survey, and the analysis plan, in addition to generating an indicative sample size that would produce significant results. This highlighted issues with the experimental design that need to be addressed before field testing, and some concerns about the validity and reliability of the survey as respondents did not always make consistent choices, did not always make trade-offs based on all attributes, and there were some attribute interaction effects. In addition, the qualitative data suggests ongoing concerns about the complexity of the survey and whether people with low literacy will be excluded. We tried to address this by reviewing the language with a specialist company and including a question about educational attainment to monitor this during field testing. Despite these concerns, the pilot did generate statistically significant results with only a small sample and these results were in the expected direction for preferences. Therefore, we decided the survey was valid enough to use in field testing. Throughout the design process we had to make pragmatic decisions weighing up validity and rigour of the final survey with the resources available and the likely implementation of the survey within the wider intervention in general practices. We prioritised keeping the survey simple and short aiming to maximise participation and completion rates, over adding additional validity and reliability tests. This is consistent with a participatory action research approach: aiming to maximise participation without sacrificing the scientific quality of a method.(19)

5. Field testing methods

This chapter describes the aims and methods used to field test the intervention. As described in Chapter 2, the overarching methodology is participatory action research (PAR). Field testing the intervention utilised systemic action research (SAR) which is a specific branch of PAR. SAR aims to stimulate system wide change through the synthesis of learning from local action research. Therefore, field testing aims to enact change at the local level in the practices, and generate systemic knowledge about the process of change across practices. The study design of the field testing will be described in detail. The results will be presented in Chapters 6 (local level effect) and 7 (systemic knowledge development).

5.1 Aims of field testing the intervention

The intervention is described in detail in Appendix 14. To recap briefly, the intervention aims to promote meaningful patient participation in general practice service improvement by combining two participatory mechanisms: *partnership working* between patients and staff in PPGs, and *consultation* with the wider public using a prioritisation survey. The intervention is based on three theoretical constructs developed from previous research:(101, 102)

- All stakeholders have multiple **credible and different knowledge** to contribute. All different forms of knowledge (experiential, presentational, propositional and practical) are valued.
- All stakeholders have **legitimate roles**. Representational legitimacy of patients and staff is increased through different approaches to representation (statistical, democratic, and symbolic) and a focus on inclusivity.
- **Power differentials** exist within and between different stakeholder groups. Deliberative partnership meetings should aim for equity of voice.

This intervention conceptualises PPGs, comprised of patients and staff, as participatory action research (PAR) groups, utilising action research cycles as a structured approach to change. The intervention provides each PPG with structured partnership work (facilitated meetings to adapt the survey, distribute the survey, and develop the action plan) to complete an inquiry process by consulting the wider patient population on their priorities for service improvement. The expectation is that patients and staff then continue working in partnership to implement the action plan drawing on their learning from the intervention work.

There were two aims of field testing the intervention:

5.1.1 PPG level of inquiry (Chapter 6)

In each individual general practice, the PPG aimed **to improve their general practice service.** PPG objectives were to:

- Agree local adaptations to the prioritisation survey,
- Survey patients' preferences for service improvement,
- Act on survey results and implement any service improvement(s).

5.1.2 Co-research group level of inquiry (Chapter 7)

The co-research group (CRG) aimed **to evaluate whether the intervention led to meaningful patient participation in general practice service improvement at a systemic level.** The CRG objectives were to:

- Investigate whether the components of the intervention worked as intended and to determine if there were any unintended effects,
- Explore the work required to achieve meaningful patient participation in service improvement across different general practices,
- Record what aspects of general practice patients can influence.

This chapter develops from Chapter 2, and outlines the methodological approach to field testing the intervention. I start by describing the overall approach, the intervention site selection and recruitment process, and the qualitative methods used to evaluate the intervention, generating evidence for the CRG level of inquiry. I then describe the sampling, distribution, and quantitative and qualitative analysis of the survey, generating evidence for the PPG level of inquiry. Finally, ethical considerations will be discussed.

5.2 Overview of the study design

Systemic action research (SAR) is a methodology within the PAR paradigm (see Chapter 2). It emerged to address criticism that knowledge generated through individual inquiry groups is often not transferable, and action tends to be local rather than systemic.(157) SAR "*locates local action inquiry within a wider system taking into account both the effects that the system has on the local issues and vice versa*"(p7).(143) SAR provides a structure for multiple parallel inquiry streams, including PAR groups, to share learning, which results in emergent knowledge (including theory) about systemic and structural barriers to action.(157) SAR has been used to: generate action for change for children in 'deprived' areas of Bristol, explore the eradication of bonded labour in India, and explore the impact of volunteering on poverty in the Philippines, Ghana, Kenya, Mozambique and Nepal.(143, 157, 238) It comprises four common characteristics (157):

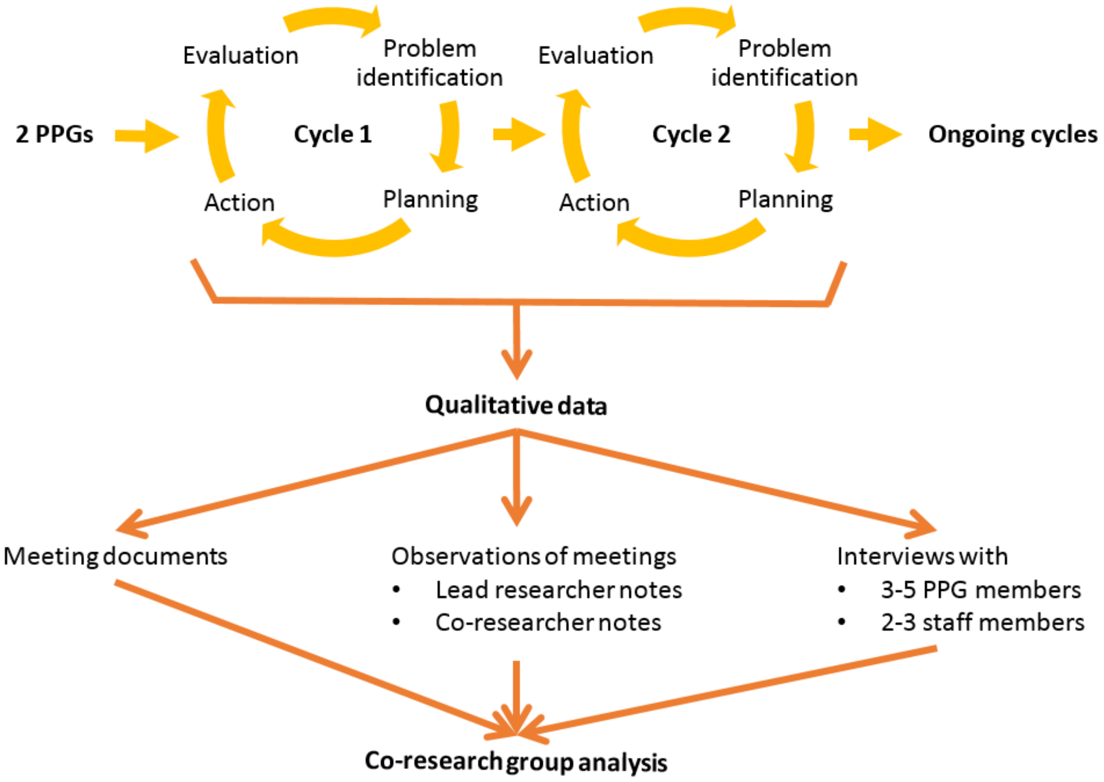
- Focus on actions which change the system,
- Connects multiple inquiries both horizontally and vertically,
- Dynamic membership,
- Emphasises resonance over representativeness.

SAR provided this project with a structure to connect the local PPG inquiry focused on improving *an individual* general practice, with the systemic CRG inquiry focused on patient participation in improving general practice *in general*. Working across general practices facilitated horizontal learning, and integrating this with the CRG enabled vertical learning to identify and influence wider system barriers to change (see Chapter 2, Figure 2.3).

The intervention conceptualises PPGs as PAR groups. PAR groups are described in detail in Chapter 2, but to recap they are multi-stakeholder groups established due to a shared aim to change their social situation, whilst also generating theory about that change.(110, 114, 135) PPGs are also multi-stakeholder groups comprised of patients and staff, aiming to improve their general practice service. Generating theory is not an explicit aim of PPGs, and many have ad hoc approaches to change.(75) However, this intervention utilises three theoretical constructs to encourage PPGs to reflect on their partnership working. In addition, it is accepted practice to use theory in evaluating complex interventions.(18) Normalisation process theory (NPT) describes how complex interventions are enacted in the real world (see Chapter 2, section 2.6 for details).(166, 168) NPT was used to develop the intervention, focusing on the barriers and facilitators to patients and staff working in partnership (see Chapter 3). The CRG used NPT during the field testing of the intervention as an analytical tool to focus on the work of patients and staff working together.

The intervention utilised action research cycles to make the aim of service improvement explicit. Each PPG worked together to identify five service improvements that could be made (problem identification). These were turned into a prioritisation survey (discrete choice experiment (DCE)) (planning). The PPG then surveyed their patient population (action) to identify priorities for change from the five chosen by the PPG and practice staff. Finally the PPG and staff reflected on the survey results (evaluation). This represented one action research cycle (cycle 1 in figure 5.1). The process was facilitated by the CRG who also collected observational data about the process. I analysed the quantitative and qualitative data from the survey, and provided each practice with their results. Each PPG, including practice staff, then worked through a second action research cycle (cycle 2 in figure 5.1): identifying an area for improvement from the survey results, planning, implementing, and evaluating the improvement. This second cycle was not facilitated by the CRG, but the CRG continued to collect observational data about the process and the work of working together. The qualitative observational and interview data collected in each PPG (see figure 5.1) was analysed both within case (i.e. at the level of the GP practice) and across cases (comparing GP practices) by the CRG. A detailed description of intervention and data collection activities, including a timeline is in Appendix 14 and 15.

Figure 5.1: Illustration of intervention process and data collection and analysis process



5.3 Site selection and recruitment

The aim of field testing the intervention was to evaluate whether and how it worked in practice, whilst learning from this process and continuing to modify the detail of the intervention. Therefore, representativeness and generalisability were not primary aims. However, the CRG were conscious of the considerable variation in general practice and PPGs, and wanted to test the intervention in more than one practice.(75, 144) Initially, we planned to work with three practices, but after the first practice we realised the field testing work was more intensive than envisaged, therefore only two practices were recruited for field testing.

Insider perspectives are a strength in PAR, and can help with recruitment.(24, 113, 239) The CRG were part of, or had experienced working with (during intervention design (Chapter 3), or a previous project (75)) eleven general practices and PPGs, in Leeds and Manchester. These eleven practices varied in: the size and composition of their patient population, the length of time they had a PPG, the structure of their PPG, and their practice organisation. As the co-researchers had existing relationships with these practices, they had insider knowledge about this variation and the history, culture, motivations, and ways of working of the individual PPGs and practices. PAR also recognises the importance of outsider perspectives to challenge assumptions, and the ethical and practical challenges posed by insider research.(113) Therefore, due to concerns about confidentiality, power, and maintaining individual co-researchers' clinical patient-doctor relationships, the CRG agreed to exclude practices where a co-researcher was a patient or member of staff. This left eight practices to recruit from. The CRG designed criteria to purposively sample general practices that would be the best to work with (see Box 5.1).

Box 5.1. Criteria and rationale for purposive sampling of general practices and PPGs (most important first as voted by the CRG)

1. The PPG are open minded to new ways of working. Some PPGs have established ways of working and thinking and do not want to change these. Practices need to be open minded to the idea that the intervention is still in a development phase rather than a completed item.
2. Both the PPG and practice are enthusiastic about the study and keen to be involved. At this early phase of testing the CRG wanted to test how the intervention worked in enthusiastic practices.
3. The PPG are stable and likely to remain in existence for the duration of the study (see also point 6 and 7). The CRG had experience of PPGs disintegrating or being disbanded by the practice.
4. The practice is open to change. The aim was to see if patients can influence change. This was unlikely to occur if practices were not interested in change.
5. The practice is located within an area of lower socio-economic status. There is limited evidence that PPGs function better in middle class areas.(71, 75, 79) There were also concerns about the literacy level required to complete the prioritisation survey (Chapter 4). Therefore, the CRG wanted to test the intervention with practices located in areas of lower socio-economic status.
6. The PPG has more than 5 members. Criteria 6 and 7 are signs of functioning PPGs (see also point 3).
7. The PPG has regular meetings.
8. At least one practice from Leeds and one from Manchester

The three highest rated practices (two in Leeds and one in Manchester) were approached in advance. The Manchester practice were unwilling to commit GP time to the intervention meetings and were excluded. Therefore, we recruited the Manchester intervention practice from outside those already known to the CRG. We advertised through local networks of GPs, practice managers, and PPG members. Many GPs approached declined stating workload issues or a lack of confidence that their PPG would do the work. Eventually a co-researcher recruited a Manchester practice that met our criteria. The intervention was staggered across the two intervention practices partly due to resources and partly to develop the intervention and share learning between the first and second practice.

PPG members and staff were given participant information in advance and then invited to a meeting to discuss the project (Appendix 26). If everyone agreed to take part they were asked to sign consent forms (Appendix 27). One patient PPG member in the Manchester practice refused to take part. After extensive discussion with the PPG, the practice staff, and the university ethics committee, a decision was made to continue with the practice involvement, and the PPG member would not attend meetings during the research. This respected the individuals' right to refuse to participate and the rights of the other PPG members to participate in the research.

Each practice were paid £750 as a sign of appreciation and for any inconvenience during the project. Individual participants were not paid. It is extremely rare for PPG members to be paid for their work, therefore payment might have set a precedent. This would have been an intervention in itself and potentially resulted in harm when the payment was not continued at the end of the project.

5.4 Qualitative data collection

5.4.1 Observational data

Observation allows the investigation of individual and group behaviour and activity as it happens in the natural world.(104) Methods of observation range from participant observation where the observer interacts with the actors they are studying, to non-participant observation where the observer attempts to minimise interaction with the actors being studied.(104) PAR explicitly aims to work with those affected by an issue, to enable them to learn from, and have ownership over the process.(24, 108) Therefore, for the first action research cycle (Figure 1) the CRG acted as participant observers. We facilitated intervention meetings using participatory methods (see Chapter 2, Table 2.2) to emphasise equal participation and democratic decision making, and encouraged reflection by asking probing questions.(239) The aim of the second action research cycle was to explore whether the PPGs could learn from the first cycle and continue the new way of working. Therefore, the CRG attempted to act as non-participant observers. However, purely non-participant observation was unrealistic, as we had become part of the group with PPG members asking co-researchers direct questions during follow up meetings. The second action research cycle in Practice 2 was cut short due to the Covid-19 pandemic. Face to face meetings were cancelled and we had to abandon our follow up.

The main activity of PPGs are PPG meetings. Although work happens between these meetings by both the patients and the practice staff, we know from previous research that this work is ad hoc and forms a very small proportion of the overall work of the practice, or the lives of the PPG members.(75) Therefore, observation was targeted at the PPG meetings, rather than continuous observation of the practice or the individuals involved. However, the PPG were encouraged to discuss and reflect on work done outside of meetings (such as distributing the survey), during the meetings and in semi-structured interviews (see below). I kept a reflective diary of contact with the PPG and practice staff between meetings. In both practices six intervention meetings were observed. In Practice 1 three follow up meetings were observed, in Practice 2 one follow up meeting was observed, but we also observed two 'normal' PPG meetings which took place during the survey dissemination and were not facilitated by the CRG. Our contact with both practices, including observation and interviews, lasted 12 months.

The CRG worked in pairs to observe PPG meetings. I attended each meeting in both general practices. I led the meeting facilitation supported by at least one patient co-researcher. To allow all co-researchers the opportunity to experience meetings, we rotated who attended the meetings. I held debriefs with the co-researchers observing meetings immediately afterwards. These discussions were audio recorded to aid future recall. All co-researchers made observational notes during meetings and wrote field notes after each meeting. This ensured that observations were from the perspective of both a patient and a GP. Observation focused on the work of the PPG and the behaviours of, and interactions between, different patients and staff. Field notes included observations regarding interactions between meetings, for example the process of negotiating access. We attempted to make an observational framework, based on NPT, to aid the process of making observational notes, but the co-researchers found this restrictive. All sets of observational notes were shared with the whole CRG and discussed in CRG meetings.

5.4.2 Documentary analysis

Documentary analysis is the systematic approach to the collection and analysis of documents.(240) It can be used alone, or triangulated with other sources of qualitative data enabling a robust and richer description of a subject. Two sets of documents were collected from both intervention practices and PPGs: documents produced before the intervention, and documents produced during the intervention. Pre-intervention documents included terms of reference, formal agendas, and minutes of meetings, which were distributed to PPG members, and in Practice 1 published on their website. These documents helped to understand how the PPGs functioned and interacted with their practices prior to the intervention. Documents produced during the intervention included summaries of meetings, a table of the results of the card sort, a summary of voting, promotional material about the survey and the results, action plans, newsletters, and photographs of flipcharts. These documents provided evidence of how decisions were made and whether the intervention resulted in new ways of working. All documents were anonymised and analysed with the other sources of qualitative data as discussed below.

5.4.3 Semi-structured interviews

Semi-structured interviews are interviews in which the researcher pre-determines the topic(s) of the interview, but allows flexibility about the order of topics and the interviewees' response.(104) A flexible interview schedule or topic guide is produced prior to the interview. This may include broad open questions and flexible follow up prompts. The emphasis of the interview may change between interviews due to the interviewee or the researcher.(104) Semi-structured interviews were conducted with PPG members and staff in each general practice. They enabled the CRG to explore specific intervention events within each practice at a deeper level and from the perspective of different individuals.

It is recognised in qualitative research that the interviewer influences the interview.(104, 241) In previous research about PPGs, staff were very open and forthcoming in interviews partly due to my role as a GP.(75) This has also been reported in other settings.(241) Equally, patient interviewees also appeared to be influenced by my GP status, referring to my role as a GP during their interviews.(75) These findings were discussed with the CRG, and as a result we agreed that I would conduct the interviews with staff, but not with patients. In addition, we agreed that patient co-researchers would conduct the interviews with patient PPG members. Peer interviewing is commonly used in participatory research as it increases the ownership of the study by co-researchers, and can provide rich and unanticipated data.(242, 243) Peer interviewing is not always possible due to time investment required of the peer interviewers.(242) Equally concerns have been raised about the skills of peer interviewers, although training, more rigid topic guides, and working in pairs have been suggested as solutions.(242, 243) Two interview training sessions were provided for co-researchers by me and an experienced researcher. The training covered the consent process, interview schedule, recording equipment, and interview techniques, with an opportunity to role play the interview.

Interview schedules were based on the four NPT constructs (see Chapter 2), and emergent findings from the observations of PPG meetings regarding the implementation of the intervention.(168) The interview schedules were designed with the CRG. Interviews can be problematic in PAR as traditionally they are done ‘to’ a participant, and the data is then analysed away from that individual.(239) To address this reflective interviews have been used to maximise the benefit of the interview for the individual interviewee.(239) Reflective interviews encourage participants to reflect, learn from their experience, and think about their future actions constructively. This is in keeping with the aim of PAR to foster participant ownership. Therefore, questions were framed to encourage interviewees to reflect, and also to share some of the interviewer’s reflections from meetings, to encourage discussion.

All patient PPG members who had taken part in at least one intervention meeting, were invited to participate in an interview. In both practices, patients were initially invited to express interest in being interviewed at the end of the first follow up meeting. This was followed by an email advertising the opportunity to all PPG members. The email was distributed by a member of staff in Practice 1, and the patient PPG secretary in Practice 2. In Practice 1, four out of 17 patients expressed an interest, and agreed to be interviewed (n=4). Three of these patients were core PPG members who had attended all intervention meetings. In Practice 2, five out of five patients expressed an interest, and four agreed to be interviewed (n=4). All patients who agreed to be interviewed were interviewed (n=8). Staff who regularly attended intervention meetings were purposively sampled and invited to participate in an interview.(244) Staff were approached directly in person and by email. In each practice three members of staff were approached and all agreed to participate in an interview (n=6). In Practice 1 interviews were held face to face in patients’ own home, or on practice premises. Due to Covid-19 restrictions Practice 2 interviews were conducted by telephone. Participant information sheets were sent out prior to interviews and informed consent was obtained in writing in Practice 1 and audio recorded in Practice 2. All interviews were audio recorded and transcribed verbatim.

5.5 Qualitative data analysis

Data collection and analysis proceeded concurrently, with early analysis informing later interview schedules, and with analysis of Practice 1 feeding into Practice 2.(192, 238) All data (observation and field notes, meeting documents, and semi-structured interview transcripts) were entered into NVivo software and analysed together.(193) Triangulating different data sources increases reliability.(189, 190) Data were analysed using thematic analysis both inductively and deductively with a constant comparison approach.(104, 192, 194) Deductive analysis used the four NPT constructs to explore the work required to implement the intervention and whether this resulted in patient participation being embedded in the practice.(168) Inductive analysis sought emerging themes outside of the NPT framework, with particular attention to power and representation which were identified in previous research.(75, 102, 194) I led the analysis familiarising myself with the different data sources and regularly sharing my initial ideas, influenced by NPT, with the CRG and my supervisors to check my understanding and increase reliability.(189, 194) Following agreement with the CRG, observational notes and each transcript were also read, and re-read by at least one other co-researcher. The co-researchers initially coded their transcripts inductively, making notes on the documents. We then held a series of analysis meetings where all codes were shared, discussed, and refined increasing reliability of the findings.(189) During these discussions codes were grouped into themes using an interactive sticky note map. Themes generated in these meetings were then mapped onto the NPT constructs and developed into an analysis framework.(194) Following this, I coded all transcripts and meeting notes using this framework. To reduce bias, each transcript was also coded by one other co-researcher using this framework.(189) Other researchers have used NPT to deductively analyse data and to organise inductively generated themes.(170, 245) When these approaches have been compared researchers found considerable consistency in the findings.(245) However, researchers have reported finding deductive analysis rigid and a less satisfying approach.(170)

5.6 The prioritisation survey

The prioritisation survey is the *consultation* participatory mechanism of the intervention (see section 5.1). A template prioritisation survey, based on a discrete choice experiment (DCE), was developed by the CRG as discussed in Chapter 4. The prioritisation survey was part of the PPG level of inquiry and aimed to support each PPG to survey their patients' preferences for service improvement. The prioritisation survey represents a two-step process of priority setting. First the PPG patients and staff agreed which five features (from the 24 developed by the CRG in Chapter 4) should be included in the survey. Then the patient population were surveyed about their priorities from the five chosen features using the DCE template. To recap, DCEs are surveys which present the relative benefits of options, and asks respondents to make choices and trade-offs between these.(184, 185) This leads to a closer approximation of how much 'value' people place on specific characteristics or attributes of a service.(176, 186) This next section will describe the process of adapting the survey, sampling, and data collection methods.

5.6.1 Overview of DCE design

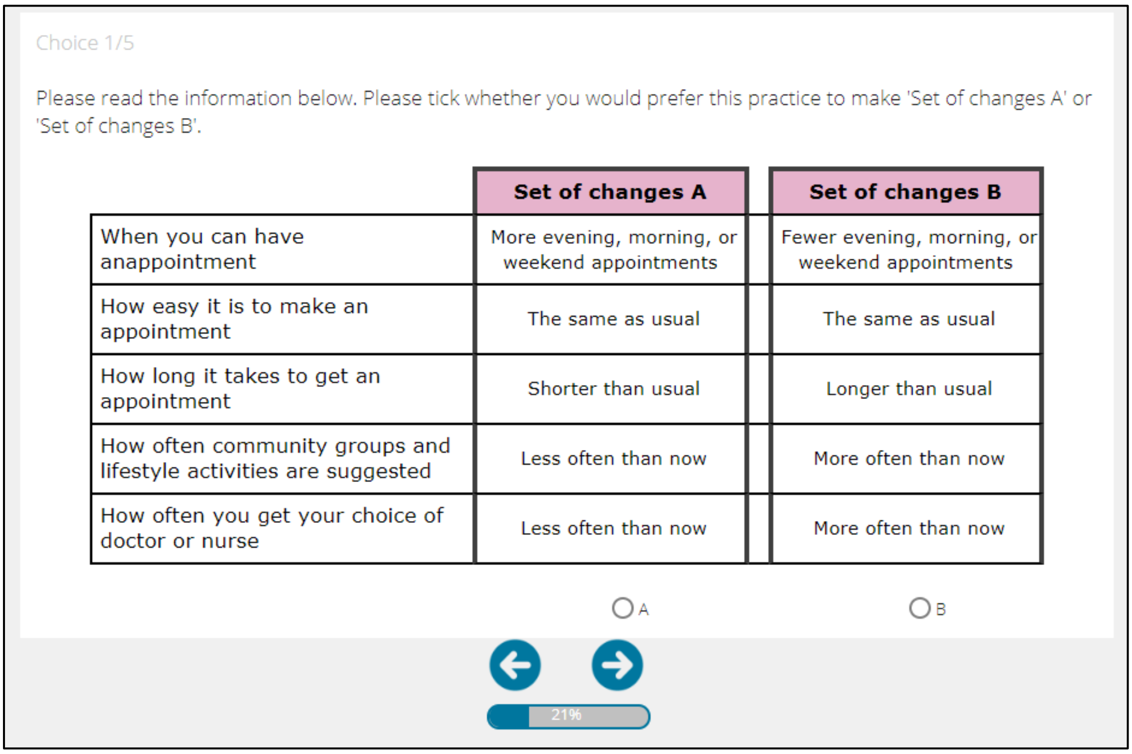
For the results of a DCE to be practically useful, the hypothetical choice decision needs to be situated in the reality of the local context and the respondent should believe their choices may result in change.(176) Therefore, as PPG members and staff choose the features to be used in the DCE, they can ensure the choices represent potential realistic change in their practice. The survey was also be personalised to the local practice to include the practice name and logo.

Each prioritisation survey was available in three modes of completion: online, paper, and ballot box. The advantages and disadvantages of the different modes of completion, identified by the CRG following the pilot, are described in Table 5.1. Each mode of the survey included:

- Instructions on how to complete the survey.
- Between one and five choice tasks (see figure 5.2 for an example of a choice task).
- Demographic questions including information about why the respondent has attended the general practice (all these questions may influence the respondents' choices).
- Free text space for further comment about the practice.
- An advertisement for the PPG to promote recruitment.

See Chapter 4 for further details and Appendix 21-23 to review the different versions of the survey.

Figure 5.2. Example of a choice task from the pilot online survey



Choice 1/5

Please read the information below. Please tick whether you would prefer this practice to make 'Set of changes A' or 'Set of changes B'.

	Set of changes A	**Set of changes B**
When you can have anappointment	More evening, morning, or weekend appointments	Fewer evening, morning, or weekend appointments
How easy it is to make an appointment	The same as usual	The same as usual
How long it takes to get an appointment	Shorter than usual	Longer than usual
How often community groups and lifestyle activities are suggested	Less often than now	More often than now
How often you get your choice of doctor or nurse	Less often than now	More often than now

○ A ○ B

Table 5.1. Potential advantages and disadvantages of the different survey modes of completion

Mode of completion	Advantages	Disadvantages
Paper	Can be completed in the practice with or without assistance from the PPG. Moderate number of choice tasks. Provides PPG volunteers with an active role.	Large amount of text may is off putting. Potentially labour intensive for PPG volunteers providing assistance. Resource implications: printing, data entry, data storage. Data quality issues: non-standard responses and missing data.
Online	Can be easily distributed to multiple patients via text message. Can be completed anywhere. Allows more choice tasks without looking burdensome. Can ensure all questions are completed before respondents can progress. No printing, storage, or data entry costs	Limited to people who use the internet. Can be completed by anyone even people not registered at the practice. Needs to be programmed.
Voting box	Can be completed in the practice with or without assistance. Looks different to a survey and potentially 'fun' and familiar. Not burdensome on the respondent.	Only one choice task per respondent. Potential for abuse, incomplete data, or rushed responses. Takes up physical space. Resource implications: printing, data entry, data storage, and changing choice tasks on the boxes every couple of days.

5.6.2 Attribute selection and experimental design

Attribute selection is a balance between what is important to respondents and what is relevant in the decision-making context.(210) The CRG developed a list of 24 features or attributes of general practice, which were tested to ensure they were relevant, important, understandable, and could result in change (see chapter 4 for details of how the features were developed and Appendix 20 for the list of features).

Each general practice is a different decision-making context. Therefore, to identify what is relevant in each decision making context, the list of 24 features were prioritised by the patients and staff in the PPG. Over the course of three facilitated meetings the 24 features were reduced to the five most relevant for that individual general practice. The facilitated meetings included a card-sort exercise completed independently by patient PPG members and the practice staff, resulting in two short lists (Meetings 1a and 1b). The patients and staff then met together to vote on the top five features to use in the survey (Meeting 2). For more detail about the content of these meetings see Chapter 3 and Appendix 14**.** Once each practice had chosen their five attributes, I used NGene software to develop d-efficient experimental designs (see Chapter 4, section 4.5).(199, 210)

5.6.3 Sampling

Each PPG, including staff, were encouraged to consider their sampling strategy. This was discussed in the PPG Training Meeting, which also included basic training in conducting surveys face-to-face, and how to complete the different modes of the survey. In addition, at the request of Practice 1 staff, a set of instructions regarding distributing the survey was produced. This included:

- the expected sample size for each mode of the survey,
- suggested text message and website wording for distributing the link to the online survey,
- instructions for changing the choice tasks for the ballot box survey,
- expectations about the support the PPG might need.

Sample size calculations for DCEs are complicated and rely on a number of factors, including the number of attributes, levels, choice tasks, the intended analysis model, and whether sub group analysis is planned.(199, 210, 246) For each of our surveys (and survey modes) the number of attributes, levels, and choice tasks differed and could not be anticipated as these were selected by the PPG members and staff during the intervention. In addition, as we were unsure of how successful survey distribution would be, our priority was to achieve a reliable main effects model and the feasibility of implementation and uptake, rather than sub group analysis. Therefore, I did not attempt a sample size calculation which would have been different for each survey and practice. Instead, I relied on a "rules of thumb" sample size calculation approach which is common in the literature.(246) There are at least three different "rules of thumb" approaches, the most simple is based on empirical experience and suggests that 20 respondents per survey is satisfactory for a main effects model.(199, 246) I adapted this based on the pilot data (see Chapter 4) which demonstrated statistically significant results based on a sample of 30 people completing the online survey (150 choice tasks). Therefore as a heuristic Table 5.2 outlines the minimum sample size for each survey mode, in each practice. This generic advice across surveys and practices is pragmatically advantageous for potential future use of the DCE in a 'real-life' context.

Table 5.2. Sample size by mode of survey completion

Survey mode	No. choice tasks per survey	Minimum surveys	Total no. choice tasks
Paper	3	50	>150
Online	5	30	>150
Voting box	1	150	>150

In this project, the end point for data collection was dependent on time. PPGs commonly conduct paper-based waiting room patient experience surveys as part of ongoing service improvement work.(75) Typically 60-120 paper questionnaires are completed over a 1-2 month cycle.(68) Electronic surveys have been tried before in general practice, resulting in an average of 194 responses over 3 months.(247) We were unable to find any prior studies using ballot boxes. To keep within the usual PPG working pattern we recommended a one to three month data collection period. The end date determined when the PPG stopped collecting completed surveys.

5.6.4 Prioritisation survey data collection and analysis

5.6.4.1 Data quality and management

The approach to calculating the response rate differed for each mode of survey completion. For the online survey we used the number of patients registered for text messages, and we calculated the overall response rate, and the completion rate (number of people who finished the survey once starting it). We had to assume mobile telephone numbers were up to date. Both practices sent two bulk text messages to all their patients registered for text messages: an initial invitation, and a reminder. We calculated the response rate for the paper survey by recording how many surveys the practice gave out and how many were completed. We were unable to record how many surveys were refused. It was not possible to calculate the ballot box response rate as the ballot box was not monitored. It was also not possible to monitor whether people completed the DCE more than once in any one version, or across versions.

A software company (ACCENT) were commissioned to format and programme, and collated the data from the online and paper modes of the survey. I collated the data from the voting box surveys. Analysis was conducted in Stata.(199) The majority of attributes had categorical levels and were analysed as categorical data. The only attribute with a continuous level was *'appointment length'* (time). This was initially included in the analysis model as continuous data, but it was clear that the relationship between levels and utility was not linear. Therefore in the final model *'appointment length'* was analysed as categorical data to avoid imposing a linear relationship.(210) Time had been included as a continuous variable to try to calculate willingness to trade time (appointment length) for other variables. As the relationship was not linear, this model did not make sense and is not reported. Descriptive statistics were used to calculate respondent characteristics. It is good practice to calculate response rates and compare responders with the population under investigation.(210) Response rates were calculated as above, but we did not have access to practice population level data for comparisons. PPGs would not normally have access to this due to confidentiality.

5.6.4.2 Validity and reliability

DCE validity and reliability measures are discussed in detail in Chapter 4. We considered the template DCE to have a degree of validity and reliability due to the extensive process of developing the attributes and levels, and the piloting work.(235) We considered adding further validity and reliability tests into the final DCEs distributed in the practices.(235) However, these tests would have involved repeating choice tasks within surveys, or adding dominated choice tasks. Both options involve reducing the amount of data collected as repeated choice tasks and dominated choice tasks are removed from the final analysis. As the main aim of field testing was to evaluate the intervention process rather than the quality of the survey, we decided it was more important to have enough data for practices to produce an action plan, rather than the quality of that data. We were uncertain about response rates, therefore I decided to maximise the number of choice tasks over further validity and reliability testing.

5.6.4.3 Model estimation

The primary aim of analysis of the DCEs was to estimate the relative strength of preference for the service improvement attributes and their levels across the practice population.(176, 210) The secondary aims, depending on response rates, were to use segmented analysis and interaction analysis to explore whether preferences differed by subgroup (e.g. gender, ethnicity) or mode of survey completion.(176, 210) In Practice 1, I conducted conditional logit regression analysis, as I had limited time and this is generally acceptable.(199) This model was appropriate as there was an unlabelled binary choice between alternatives (respondents had to choose A or B).(199) However, this model does not take into account the fact that the data included panel data. Panel data describes multiple observations from one respondent that is generated when respondents complete more than one choice task each.(199, 210) This is relevant as the paper survey included three choice task and the online surveys five choice tasks. Panel data for one respondent does not have the same random variation as data across respondents, and therefore should be analysed taking this into account.(199, 210) Therefore in Practice 2, I built in extra analysis time, and compared the conditional logit model with a mixed logit model which accounts for panel data.(199, 210) Models were compared using the Bayesian information criteria (BIC), which is a statistical test of the fit of a non-nested model.(199, 248) A lower value indicates a better fit. All attributes included one level describing '*usual care'*, with the other levels *'better'*, or *'worse'*, relative to this. The reasoning for this is outlined in Chapter 4. Data was analysed with the *'usual care'* level as the baseline. This decision was made after trying to explain the results in a format that would stimulate action planning. Comparing results to care which is worse than usual did not make sense as this was not something that the practices were aspiring to.

5.6.4.4 Free text data analysis

All formats of the survey included a large free text box which encouraged respondents to add qualitative feedback on the practice features in the survey or any other practice features they would like to see change. The free text responses were entered into NVivo and analysed thematically.(104, 193) Themes were descriptive and based on practice features discussed and whether the comments were positive or negative. This was a simple analysis I conducted, representing the pragmatic approach that would be taken due to limited resources if the intervention were being implemented in the 'real-world'. All the free text responses were shared with the practice.

5.7 Ethical considerations

Participatory research explicitly aims to be ethical research and this is discussed in detail in Chapter 2.(187) There were four ethical issues specifically related to the intervention field testing.

1. *Burden of the work on the patients and staff and the need for incentives.* All general practices have a contractual duty to have a PPG. Therefore, the major components of the intervention were already happening in some form in most general practices. The intervention is different from normal practice in the detail involved in these components and the number of meetings taking place. Therefore, the intervention was not burdensome compared with usual practice. However, the observation and interviews were additional work and this is why we offered payment to the general practices. As mentioned above, payment to patients was deemed inappropriate as it would be an intervention in itself.
2. *Burden of work on the co-researchers conducting the field testing.* The CRG were involved in designing all aspects of the study, had training and support, and we made contingency plans and continuously negotiated workload. The co-researchers were paid for their work, and received expenses.
3. *Anonymity of participants.* In both practices there were one or two individuals with specific roles (e.g. Practice Managers) and unique role names. To ensure anonymity groups and individuals were assigned identification numbers. This was emphasised in participant information leaflets.
4. *Individuals' rights to take part in research or not.* As discussed above, we initially stated that practices would only take part if all patients and staff agreed. However, in Practice 2, one person did not want to participate and did not want to give reasons.

> We balanced their right to not participate with the rights of the rest of the patients and staff who were keen to participate.

The University of Leeds Medical Research Ethics Committee approved the intervention field testing MREC 18-009 (Appendix 25).

6. Field testing results: PPG level of inquiry

This chapter describes what happened in the two PPGs and practices field testing the intervention, and whether the intervention stimulated patient centred service improvement in the general practices. I will focus on what happened during the intervention meetings, the survey results, and how the action plans were developed. I will initially describe how patients and staff adapted the survey to their local needs, the distribution of the survey, and the survey results. I will then describe the action plans that patients and staff agreed together in both practices, and the implementation of the action plan in Practice 1. Practice 2's involvement was curtailed due to Covid-19. Chapter 7 will address the effect of the intervention on the relationships between patients and staff when they attempted meaningful patient participation in general practice service improvement.

The intervention is described in detail in Appendix 14. The aims and objectives of field testing the intervention are discussed in Section 5.1. The results presented below explore whether these objectives were achieved.

6.1 Practice and participant recruitment

Site selection and recruitment are discussed in Section 5.3. Practice 1 was our highest rated practice according to our criteria and agreed to participate immediately. Three practices were directly approached before the fourth practice, Practice 2, agreed to participate. Both practices were similar in terms of the demographics of their patient populations, but very different as organisations and in the organisation of their PPGs (Table 6.1).

Table 6.1. Practice and PPG characteristics

Practice/PPG characteristics	**Practice 1**	**Practice 2**
Size of patient population*	6,713	7,815
Deprivation*	3rd most deprived IMD^ 31.3	2nd most deprived IMD^ 39.5
Patients reporting positive experience*	90.8%	75.9%
Proportion of ethnically white patients	51.3%	42.4%
Who leads the PPG	Practice led	Patient led
How often PPG meet	Quarterly	Monthly
Main role of PPG	Information giving	Campaigning
Number of patient PPG members	6-12	6

**Data from Public Health England: National General Practice Profiles [accessed 5th March 2020].(148) ^IMD = Index of Multiple Deprivation (149)*

Patients and staff took part in intervention meetings in both practices. There were six intervention meetings in each practice:

- Introductory meeting: Meeting 0 (M0),
- Card sort meetings with patients and staff respectively: Meeting 1a and 1b (M1a and M1b),
- Voting meeting: Meeting 2 (M2),
- Training meeting (TM),
- Results and action planning meeting: Meeting 3 (M3).

In Practice 1 there were three Follow Up Meetings (FU1-3) and one Follow Up Meeting in Practice 2. In Practice 2 there were also two Normal Meetings (NM), which took place when the survey was being distributed. These were observed but not facilitated by the CRG.

Table 6.2. Patients and staff who attended meetings in Practice 1

Participant No.	M0	M1a	M1b	M2	TM	M3	FU1	FU2	FU3
1 New Engagement Lead	X	(X)	X	X	X	X	X	X	X
2 Patient	X								
3 Patient	X	X						X	X
4 Patient	X	X		X	X	X	X	X	X
5 Patient	X					X	X		X
6 Patient	X								
7 Patient	X							X	X
8 Patient	X	X		X		X		X	X
9 Patient	X								
10 Old Engagement Lead	X		X	X					
11 Patient	X	X							
12 GP Partner	X		X			X			
13 Patient	X	X		X	X	X	X	X	X
14 Practice Manager	X		X	X		X	X	X	X
15 GP Partner	(X)		X	(X)					X
16 Patient		X							
17 Patient		X			X	X			
18 Patient		X		X					
19 Patient		X							
20 Patient		X		X	X	X	X	X	X
21 Patient		X		X	X				
22 Patient		X							
23 GP Partner				X					
24 Patient						X	X		X
25 Patient						X			
26 Patient						X			
27 Patient						X	X		
28 Patient							X	X	X

(X) = appeared briefly, but did not stay for the meeting. Grey shading = staff member.

Table 6.3. Patients and staff who attended meetings in Practice 2

Participant No.	M0	M1a	M1b	M2	TM	NM	NM	M3	FU1
1 Patient Chair	X	X		X	X	X	X	X	X
2 Patient Secretary	X	X		X	X	X	X	X	X
3 Patient	X	X		X		X		X	X
4 Patient	Did not consent								
5 Reception Manager	X		X	X	(X)	X			X
6 Receptionist	X			X		X			
7 Practice Director			X					X	X
8 GP Partner			X						
9 Receptionist			X	X					
10 Admin Team			X	X					
11 Receptionist			X	X					
12 GP Partner			X						
13 Salaried GP			X	X		X		X	
14 Patient				X		X			
15 Patient				X		X		X	X
16 Patient								X	

(X) = appeared briefly, but did not stay for the meeting. Grey shading = staff member.

Table 6.4. Staff members who attended M1b in Practice 1 and Practice 2

Role	**Number of participants**	
	Practice 1	**Practice 2**
Practice Manager	1	1
Reception Manager		1
Engagement Lead	2 (Old and New)	
GP Partner	2	2
Salaried GP	1	1
GP Trainee	2	1
Receptionist	4	6
Medical Secretary/Admin	2	4
Advanced Nurse Prescriber	1	
Practice nurse		1
Health Care Assistant	1	1
Social Prescriber	2	
Total	18	18

The number and roles of the participants present in each meeting are shown in Tables 6.2-6.4 below. PPG members and staff demographic characteristics were not recorded as we were aiming for the intervention to fit with normal practice. Observational notes included subjective interpretations of participants' age, gender, and ethnicity. These characteristics have been omitted to maintain anonymity. In both practices the majority of patients were over 50. In Practice 1, patient participants were split almost evenly between White and Black ethnicity. In

Practice 2, all participants were White. In both practices some patients only attended one meeting, but a cohort attended all meetings. At least two members of staff attended every required intervention meeting. Staff engagement in M1b was very high (see also Chapter 7).

6.2 Attribute selection results

In both practices, attributes and levels to include in the prioritisation survey were selected from the 24 designed by the CRG (see Chapter 4 and Appendix 20). Each PPG followed a two-step process to select their top five attributes.

6.2.1 Card sort meetings (M1a and M1b)

The first stage of selecting attributes involved patients and staff meeting separately (M1a and M1b) to sort attribute cards into three groups:

- Green – attributes they were interested in being in the survey,
- Red – attributes that they did not want to be in the survey,
- Orange – attributes that they were not sure about.

They were given the following instructions to decide which group to put the attributes into:

- Which of these features would you be interested in finding out whether patients at [name of practice] think they are a priority for change?
- The features you pick should be things you think it is possible to do something about and you are interested in acting on them.

The results are presented in Table 6.5. Attributes were taken forward to the next stage if either the patients or staff placed them in the green category (20 attributes in Practice 1, and 16 attributes in Practice 2).

All features generated discussion in both patient and staff meetings (M1a and M1b). For a minority of the features the patients wanted more information from the staff before passing judgement. In both practices, many patients struggled with the card sort exercise (see Chapter 7). Staff were much more confident at putting attributes in the red category. This was usually because they felt changing the attribute was beyond their control.

Table 6.5. Results of the card sort of attributes by both patients (pt) and staff in practice 1 and 2.

No	Attribute	Practice 1			Practice 2		
		Pt	Staff		Pt	Staff	
1	How long your appointment lasts	G	G	Agree	O	G	Almost agree
2	How many days you wait to get an appointment	G	O	Almost agree	G	R	Not able to change this
4	How you can talk to the doctors and nurses (telephone, online)	G	G	Agree	O	O	Agree
5	When you can have an appointment	G	R	Not able to change this	G	R	Not able to change this
6	How easy is it to get a home visit	O	R	Almost agree	O	R	Almost agree
7	How easy it is to book an appointment	G	R	Not able to change this	O	R	Almost agree
8	How the doctors and nurses treat you	O	G	Almost agree	G	R	Not able to change this
9	How well the doctors listen and pay attention to you	G	G	Agree	O	R	Almost agree
10	How involved you are in making choices about your care	G	G	Agree	O	R	Almost agree
11	How many problems you can discuss in your appointment	G	R	Not able to change this	G	R	Not able to change this
12	How often community groups and lifestyle activities are suggested	O	G	Almost agree	G	G	Agree
14	How you are supported to manage your own health	G	G	Agree	G	O	Almost agree
15	How well your doctor or nurse knows your medical history	G	R	Not able to change this	G	G	Agree
16	How well your doctor or nurse knows you as a person	G	R	Not able to change this	O	R	Almost agree
17	How often you get your choice of doctor and nurse	G	R	Tried & failed before	G	O	Almost agree
19	How many services are offered by the practice	O	G	Almost agree	G	R	Not able to change this
20	How much patients are charged for requests for letters of support	O	R	Almost agree	G	R	Staff not interested
21	How interpretation services are provided	O	G	Almost agree	G	R	Already provide
22	How the practice treats different groups of patients	G	R	Already prioritised	O	R	Almost agree
23	How the receptionists treat you	O	G	Almost agree	G	G	Agree
24	How well the practice protects your privacy at reception	G	R	Not able to change this	G	O	Almost agree
25	How warm, clean, and tidy the environment is	R	R	Agree	R	G	Patients not interested
27	How often you are asked about your experience at the practice	O	O	Agree	O	G	Almost agree
30	How the staff respond to feedback and complaints	G	G	Agree	O	R	Almost agree
	Total number: G	15	11		13	6	
	O	8	2		10	4	
	R	1	11		1	14	

6.2.2 Voting meeting (M2)

The second stage of selecting the attributes was a joint meeting where patients and staff voted on which attributes should be the five in the final survey. Individual voting happened at the beginning of the meeting, followed by a discussion, then a final opportunity to vote again. In both practices during the discussion, staff explained why they did not think it was possible to change some of the attributes. Patients, especially in Practice 1, championed certain attributes which resulted in them getting more votes in the second round of voting. In both practices everyone in the meeting changed their votes between the first and second vote. See Tables 6.6 and 6.7 for the results.

The voting was slightly different in each practice, based on refinement of the process after Practice 1. In Practice 1 each person voted for five attributes. People not able to make the meeting (both PPG members and staff) were encouraged to vote online before the meeting. We did not distinguish between attributes which both patients and staff selected as green, or where one party had selected the attribute as orange or red. The top five attributes changed between the first and second vote.

In Practice 2, each person was asked to rank their top five attributes by giving 5 points to their most preferred attribute, down to one point for their lowest preference. Group weighted scores were then calculated. People who could not make the meeting were encouraged to vote online prior to the meeting, but no one did. To make the number of attributes more manageable during the meeting, attributes were split into those that both patients and staff had selected as green or orange, and those that one party had selected as red. The same five attributes would have been chosen whether we had used voting or ranking. The order of the attributes would also have been similar, except for the lowest ranking attributes (12 and 17). More people voted for 17, but 12 was ranked as being more important.

The five attributes chosen to go into each survey were considered to be priorities by both patients and staff. All participants felt that depending on the results of the survey, they would be able to act to improve the attributes chosen. There was no overlap across the two practices in terms of which attributes were chosen. Practice 1 asked for minor wording changes to the attributes to reflect the roles in their practice (for example ‘receptionists’ became ‘patient support staff’), Practice 2 did not request any changes. In Practice 1 the attributes in the final choice task were ordered numerically. In Practice 2, the attributes in the final choice task were ordered in a logical sequence of how they would be experienced by a patient seeking and attending an appointment. The final five attributes for both practices are shown in Tables 6.8 and 6.9.

Table 6.6. Practice 1 voting results

	First vote					Second vote		
Feature Number	Patients	Staff	Pts online	Staff online	**Overall**	Patients	Staff	**Overall**
1. Length	2			1	**3**			
2. Wait	2		1	3	**6**	3		**3**
4. Contact	3	2	2	1	**8**	2	2	**4**
5. When	2			1	**3**			
7. Ease	1	2		4	**7**	1	2	**3**
8. Dr treat	3	1	1	1	**6**			
9. Listen	2	1	1	2	**6**	5	3	**8**
10. Decisions	3	2	1	7	**13**	4	4	**8**
11. Problems	2	1	2		**5**	3	1	**4**
12. Community		1		2	**3**			
14. Support	1	2		4	**7**			
15. History	1				**1**			
16. Known	1				**1**			
17. Choice Dr								
19. Services	3	4	1	3	**11**	3	4	**7**
21. Interpreter								
22. Equity				1	**1**			
23. Reception	1	2	1	2	**6**	4	2	**6**
24. Privacy				2	**2**			
30. Feedback	3	2		1	**6**	5	2	**7**
Total	30	20	10	35	**95**	30	20	**50**

Green shading = top 5 in first vote. Yellow shading = top 5 in second vote.

Table 6.7. Practice 2 voting results

	First vote			**Second vote**		
Feature Number	**Patients**	**Staff**	**Overall**	**Patients**	**Staff**	**Overall**
1. Length	14	25	39	20	24	44
12. Community	5	9	14	13	6	19
14. Support	11	9	20	15	18	33
15. History	20	26	46	19	27	46
17. Choice Dr	7	5	12	7	6	13
23. Reception	2	11	13	1	8	9
24. Privacy	2	2	4	0	1	1
27. Quality	0	3	3	0	0	0
2. Wait	4	0	4	0	0	0
5. When	2	0	2	0	0	0
8. Dr treat	8	0	8	0	0	0
11. Problems	0	0	0	0	0	0
19. Services	0	0	0	0	0	0
20. Charged	0	0	0	0	0	0
21. Interpreter	0	0	0	0	0	0
25. Environment	0	0	0	0	0	0
	75	90	165	75	90	165

Green shading = top 5 in first vote. Yellow shading = top 5 in second vote. Grey shading = attributes either staff or patients placed in red category.

Table 6.8. Attributes and levels chosen in Practice 1

	Practice 1 attributes	**Practice 1 levels**
9	How well the doctors and nurses listen and pay attention to you	Less carefully than usual
		No change from usual
		More carefully than usual
10	How involved you are in making choices about your care	Less involved than usual
		No change from usual
		More involved than usual
19	How many services are offered by the practice	Fewer services than now
		The same services as now
		More services than now
23	How the patient support staff treat you	More neutral and business-like than usual
		No change from usual
		More friendly and personal than usual
30	How the staff respond to feedback and complaints	Slower to act than usual
		The same as usual
		Quicker to act than usual

Table 6.9. Attributes and levels chosen in Practice 2

	Practice 2 attributes	**Practice 2 levels**
17	How often you get your choice of doctor and nurse	Less often than now
		No change from now
		More often than now
15	How well your doctor or nurse knows your medical history	Less well than now
		No change from now
		Better than now
14	How you are supported to manage your own health	Less support and less personal advice than usual
		No change from usual
		More support and more personal advice than usual
12	How often community groups and lifestyle activities are suggested	Less often than now
		No change from now
		More often than now
1	How long your appointment lasts	2 minutes shorter than usual
		The same length as usual
		5 minutes longer than usual
		10 minutes longer than usual

6.3 Results of the survey

6.3.1 Response rates and respondent characteristics

Both practices chose to distribute the survey using all three modes of completion. Data about the survey distribution and response rates are shown in Table 6.10. Respondent characteristics are presented in Tables 6.11 and 6.12

Table 6.10. Survey distribution and response rates.

	Practice 1	Practice 2
Number of days the survey was live	23	37 (online: 8 days)
Number of patients registered for text messages	1900	4000
Number who clicked on the survey link	1177	791
Number who read the introduction only	930	576
Number who did not complete the choice tasks	77	52
Number who did not complete the demographic questions	10	10
Number who complete the whole survey	160	153
Online survey completion rate	13.6%	19.3%
Online survey response rate	**8.4%**	**3.8%**
Number of PPG members volunteering in the waiting room	6	2
Number of paper surveys handed out	138	136
Number of paper surveys returned	115	116
Paper survey response rate	**83.3%**	**85.2%**
Number of ballot box surveys completed	58	74
Total number of surveys	333	343
Total number of choice tasks	1203	1187

Table 6.11. Practice 1 survey respondent characteristics

		Overall	Paper	Online	Ballot box
Number of responses		333	115	160	58
Response rate		Unknown	83.3%	8.4%	Unknown
Age:	Range (min-max)	10-91	10-85	11-79	26-91
	Average	52	50	53	56
Gender:	Female	66.1%	62.5%	67.5%	69.6%
	Male	33.5%	37.5%	31.8%	30.4%
	Other	0.3%	0%	0.6%	0%
Ethnicity:	White	62.8%	45%	72.4%	71.4%
	Mixed	4.3%	9.9%	0.6%	3.6%
	Black	17.3%	23.4%	15.4%	10.7%
	Asian	11.8%	15.3%	9%	12.5%
	Other	3.7%	6.3%	2.6%	1.8%
Education:	School	17.8%	30.5%	11%	13%
	College	22%	29.5%	18%	18.5%
	University	60.2%	40%	71%	68.5%
Have a long term condition		58%	56.9%	57.4%	61.8%
% patients would recommend		81.5%	87.3%	77.8%	80.4%

Table 6.12. Practice 2 survey respondent characteristics

		Overall	Paper	Online	Ballot box
Number of responses		343	116	153	74
Response rate		Unknown	85.2%	3.8%	Unknown
Age:	Range (min-max)	11-87	16-82	19-77	11-87
	Average	46	44	45	49
Gender:	Female	68.6%	75%	66.2%	64.8%
	Male	31.1%	25%	33.1%	35.2%
	Other	0.3%	0%	0.7%	0%
Ethnicity:	White	51.1%	43%	52.7%	59.2%
	Mixed	5%	4%	6%	4.2%
	Black	22.1%	21%	23.3%	21.1%
	Asian	13.7%	19%	12%	9.9%
	Other	38.1%	13%	6%	5.6%
Education:	School	19%	19.8%	17.6%	21.2%
	College	30.2%	37.4%	26.4%	28.8%
	University	50.8%	42.9%	56.1%	50%
Have a long term condition		50%	53.5%	47%	51.4%
% patients would recommend		61.4%	65.7%	59.3%	59.7%

6.3.2 Data quality

The response rate was similar to previous general practice waiting room surveys for the paper survey and the online survey separately, but greater overall.(68, 247) All modes of survey completion were analysed together as the ballot box sample was too small to analyse separately and I did not want to lose the data.

The online response rate in Practice 2 was considerably lower than Practice 1. There are a number of possible explanations. We are unable to confirm the accuracy of telephone numbers, although PPG members confirmed text messages were sent out. Due to a technical issue in Practice 2 the text messages were only sent out one week before the end of data collection, shortening the data collection period. Equally, Practice 2 had a high proportion of non-English speaking patients. However, the completion rate was higher than in Practice 1 suggesting inaccurate telephone numbers, and shorter duration of data collection are more likely to account for the different response rate.

In both practices the ballot box surveys were left out in the waiting room and patients could complete them at any time. At some points the paper surveys were also left out in the waiting room. However, paper surveys were only consistently completed in high numbers when PPG members were present and supported distribution. As discussed in Chapter 5 we were unable to calculate response rates for the ballot box survey. Neither practice had data on the footfall in the waiting room to estimate a response rate.

We only had access to limited nationally published practice demographic data for comparison.(148) However, compared to this respondents appeared to be more likely to be female, White, and we suspect university educated (based on socio-economic status). Tables 6.11 and 6.12 demonstrate that in both practices, the paper version of the survey had the most diverse sample. They were younger, more ethnically diverse, and less educated.

6.3.3 Validity and reliability

Validity and reliability are discussed in detail in Chapter 4: Section 4.5, and Chapter 5: Section 5.6.4.2. In Practice 1, all results were statistically significant except the patient support team being *'more friendly and personal'*. All results were in the expected direction. In Practice 2, only two levels were statistically significant. However, six levels showed non-significant trends in the expected direction, and only '*less support'* and *'more community and lifestyle advice'* were not in the expected direction. Statistically significant results, and results in the expected direction are both indicators of internal validity.(235)

6.3.4 Model estimation

In Practice 1, I used a conditional logit model for the analysis. In Practice 2, I compared a conditional logit and mixed logit models. The mixed logit model had a better fit: BIC for the conditional logit model was 2322, and for the mixed logit model was 1611 (a lower number represents a better model). Data was analysed with '*usual care'* as the baseline as discussed in Chapter 5; Section 5.6.4.3. Therefore the results demonstrate the value of an attribute improving, and the value of it not getting worse (or staying the same). In both practices, patients valued attributes not getting worse more than they valued attributes improving. This suggests patients value the care they already receive.

The attribute patients in Practice 1 valued most was *'How well the doctors and nurses listen and pay attention to you'.* They valued it not getting worse (1.173 $p<0.0001$) more than it improving (0.807 $p<0.0001$) (Table 6.13 and Figure 6.1). Patients valued both levels more than any other attribute level.

The attribute patients in Practice 2 valued most was not having appointments *'2 minutes shorter'* (1.026 $p<0.0001$) (Table 6.14 and Figure 6.2). There was a non-significant trend for patients wanting longer appointments, but the mixed logit model suggests this relationship is not linear and although patients did not want shorter appointments, they also did not want really long appointments (Figure 6.2). The only other statistically significant result is that patients did not want their *'doctor or nurse to know their medical history less well than now'* (0.767 p=0.034). Patients did not have a strong preference for the feature *'how often community groups and lifestyle activities are suggested*'. This result was also observed in the pilot survey (Chapter 4). The qualitative pilot interviews suggested this attribute was understood and some people did not want advice.

The mixed logit model in Practice 2 demonstrates wider confidence intervals than the conditional logit model. This is due to the way it treats panel data (multiple choice tasks completed by the same person, see also section 5.6.4.3). The wider confidence intervals represent heterogeneity between individuals. Sub group analysis, by gender, ethnicity, health status, patient satisfaction, and mode of completion, were attempted to explain this heterogeneity. However, there were no significant results as the sample size was too small to achieve subgroup differences. In Practice 1, it appeared that Black, Asian and minority ethnic patients reported worse experiences of care than White patients. This has been reported across UK general practice.(249, 250) Subgroup analysis was attempted, but there was no significant difference.

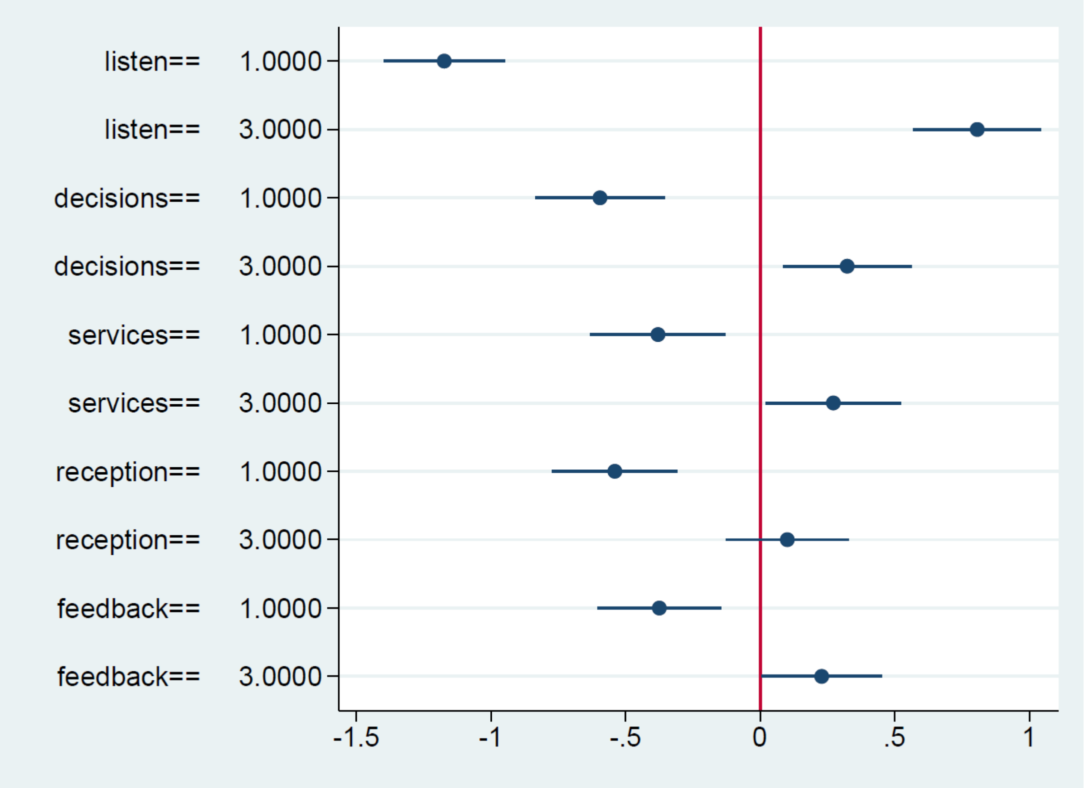
A number of attempts at presenting the results graphically were made. Two page summaries presented to both practices are shown in Appendix 30 and 31. Figures 6.1 and 6.2 respectively were not shared with the PPGs as we did not think they were easy to understand.

Table 6.13. Practice 1 conditional logit model results

Attributes and levels	**Coefficient**	**P value**	**95% Confidence Interval**	
Listen less than now	-1.173	0.000*	-1.398	-0.949
Listen more than now	0.807	0.000*	0.570	1.044
Involved in decisions less than now	-0.595	0.000*	-0.835	-0.355
Involved in decisions more than now	0.324	0.008*	0.085	0.562
Fewer services than now	-0.379	0.003*	-0.630	-0.128
More services than now	0.272	0.034*	0.020	0.524
Patient Support Team neutral and business-like	-0.540	0.000*	-0.772	-0.307
Patient Support Team friendly and personal	0.101	0.386	-0.128	0.330
Practice respond to feedback slower than now	-0.374	0.001*	-0.604	-0.145
Practice respond to feedback faster than now	0.229	0.045*	0.005	0.453

**significant result.*

Figure 6.1. Graph showing the relative value of features in Practice 1 (conditional logit model).



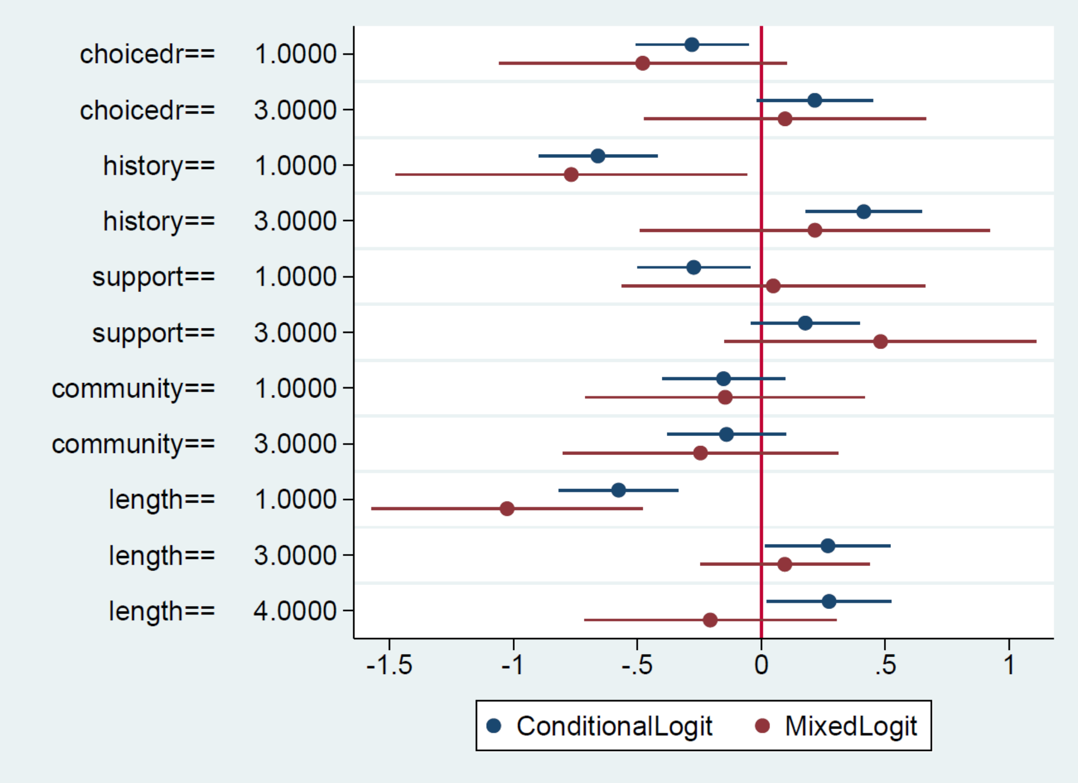
1.0000 = worse than usual care. 3.0000 = better than usual care.

Table 6.14. Practice 2 mixed logit model results

Attributes and levels	**Coefficient**	**P value**	**95% Confidence Interval**	
Less choice of doctor or nurse	-0.478	0.106	-1.059	0.102
More choice of doctor or nurse	0.096	0.741	-0.474	0.666
Less well known medical history	-0.767	0.034*	-1.476	-0.058
More well known medical history	0.217	0.547	-0.489	0.922
Less support to manage your own health	0.048^	0.877	-0.563	0.660
More support to manage your own health	0.482	0.133	-0.147	1.110
Fewer community groups and lifestyle activities	-0.146	0.612	-0.708	0.417
More community groups and lifestyle activities	-0.245^	0.387	-0.801	0.310
Appointments 2 minutes shorter	-1.026	0.000*	-1.573	-0.478
Appointments 5 minutes longer	0.095	0.586	-0.246	0.436
Appointments 10 minutes longer	-0.206	0.427	-0.714	0.302

**significant result. ^ result not in the expected direction.*

Figure 6.2. Graph showing the relative value of features in Practice 2 (conditional and mixed logit models).



1.0000 = worse than usual care. 3.0000 and 4.0000 = better than usual care.

6.3.5 Free text results

A significant proportion of respondents left free text comments: 159 (47.7%) in Practice 1, and 179 (52.2%) in Practice 2. The themes discussed in these comments included all the attributes in each survey, the additional themes are summarised in table 6.15. Many themes included positive and negative comments. Both practices were given detailed reports of the themed free text responses.

In addition to the themes above, 33 respondents (10%) in Practice 1, and 5 respondents (1.5%) in Practice 2, commented on the survey format (Table 6.16). All responses were negative, and overall cast doubt on the internal reliability of the survey, as some respondents admitted to answering randomly. Perhaps more significant are the comments from patients angry about the survey and the potential this has to affect patient-practice relationships. In addition, patients in both PPGs expressed similar reservations about the survey during the Training Meeting.

Table 6.15. Additional themes to survey attributes discussed in the free text boxes.

Practice 1 Themes	**Practice 2 Themes**
Appointments out of hours	Getting through on the telephone
Waiting time for an appointment	Booking an appointment
Being able to see the same GP	Waiting time for an appointment
Longer appointments	Out of hours appointments
Difficult appointment system	Alternatives to face to face appointments
Not getting through on the phone	Online services
Type of appointments (online, email)	Privacy at reception
Late running clinics	Receptionists
Administration issues	Doctors and nurses
Patient centred practice	Clinics running late
Car parking	Administration
Waiting room issues	Waiting room and building issues
More male GPs	Services offered by the practice
Patient group issues	Patient safety
	Practice accessibility
	Patient group issues

Table 6.16. Examples of respondent quotes about the discrete choice experiment.

"The first few sections of this questionnaire are extremely difficult to understand and complete. I have been professionally involved in social research and I find the way that it is structured completely misguided and off putting. I have not completed it in full as I don't have the time needed to offer any constructive answers. Please disregard all of the information I have provided in the survey apart from this note!"
"It was very difficult to follow the confusing questionnaire. I made random selections as the questions seemed to repeat each other with responses that contradicted each other. I think it should be redesigned and be clearer."
"I think this survey is really poor and don't want to participate. The first question asks me to choose between more services and less people time. It really put my back up and seems manipulative. Please remove me from your consultation list. I'm disappointed."
"This survey is absurd, it doesn't make sense. I've since found out it was devised by a doctor so that's understandable as to why regular people can't understand it!"
"I found answering the questions hard because of the choices involved, which makes me realise what you have to work with all the time."
"Set A is self-contradictory - it is impossible to be more involved in making choices about my care if the doctors and nurses are listening less carefully!"

6.4 Action planning results

After presenting the results to patients and staff in Meeting 3 (M3), we asked all participants to think about the results and answer the following question:

What could we/the practice do to improve area(s) prioritised by survey?

Participants took part in a flexible brain storm (Chapter 2, Table 2.2) providing suggestions on sticky notes which were organised into themes (Appendix 32 and 33). These themes were combined into 3 action points and presented back to the practices (Tables 6.17 and 6.18). Some participants stated that they were not confident in the survey results or how to interpret them. However, they were all still happy and able to complete the action planning exercise. This may explain why the majority of the sticky notes do not appear to link to the main survey result. This was especially in Practice 2 where the survey results were less clear.

Some of the sticky note suggestions were clearly linked to free text responses in the survey. This included ‘car parking’ in Practice 1, and ‘improving privacy in the reception area’ in Practice 2. There were a significant number of passionate and emotive free text comments about the privacy issue in Practice 2. Privacy was discussed in the voting meeting (M2), but only received 4 ranking votes, suggesting PPG members were not aware of it being a big problem. Including a free text comment box was therefore essential to allow the wider patient population to influence the action planning.

In addition to the topics raised by the survey, the action planning meeting also resulted in the championing of topics which were not in the survey (e.g. ‘increased funding’ in Practice 1, and ‘alternative appointment systems’ (triage, telephone and video appointments) in Practice 2) or issues that the survey results indicated were not a priority for the patient population (e.g. ‘increased services’ in Practice 1, and ‘community groups’ in Practice 2). Some of these became action points despite not being highly rated by the survey.

Table 6.17. Action plan for Practice 1.

	Description of action
1	Improving communication with the patient population. *Focusing on raising awareness of the services the practice offer and do well (newsletter, waiting room TV, online – all with patient contributions).*
2	Ethnicity and improving patient experience. *Actively investigate differences in patient experience by ethnicity. Work with local community groups to explore issues and ways of improving the service*
3	Maximising patients feeling listened to. *Peer led non-violent communication skills training for all staff. Helping patients prepare for their appointments, including raising awareness of when doctors work to improve continuity of care.*

Table 6.18. Action plan for Practice 2.

	Description of action
1	Improving the appointment system and experience of booking appointments. *Short term – raising awareness existing services (e.g. online appointment bookings) with patients and receptionists. Improving privacy around the reception area.* *Long term – exploring potential changes to the appointment system.*
2	Supporting patients to manage their own health. *Raising awareness of local community resources via the noticeboard and encouraging clinicians to promote these. Setting up peer support groups. Explore group consultations*
3	Making the patient group more accessible. *Change the name to "patient and staff group". Explore different meeting times.* *Advertise meetings via text message.*

6.5 Implementation of the action plan

Practice 1 implemented or started to implement all of its action plan (Table 6.19). In follow up interviews the staff agreed that they might have acted to improve the website and waiting room TV (including staff profiles) without our project, but all the other actions were as a result of the project.

Table 6.19. Actions implemented in Practice 1.

Plan no.	Action
	Survey results displayed on the website.
1	Two quarterly newsletters produced with brief articles from PPG members and local community leaders.
1	Local schools and universities contacted by PPG members regarding the possibility to help make films for the waiting room TV.
1	Website updated with information about services
1&3	Staff photographs and profiles added online and in the practice.
2	Staff read up on issues related to ethnicity and patient experience. They also discussed these with local community groups. There were plans to discuss this in a PPG meeting, but every time it was on the agenda the meeting ran out of time.
3	Practice rebranded as "the listening practice".
3	Nonviolent communication skills training delivered for the patient support team and clinical team by one of the GP partners.
3	PPG members ran one waiting room "listening event", with more planned.
3	Stall held at local large community event, where staff and patients listened to the local public about what they value about general practice and offered blood pressure checks.
3	Leaflets helping patients to prepare for appointments that were developed during a previous project, were distributed in the waiting room.

Unfortunately Covid-19 meant that Practice 2 we were unable to implement their action plan. Interestingly, Covid-19 resulted in the national imposition of telephone triage appointment systems, and video consultations. Practice 2, like all other practices adapted quickly, despite stating that these models were impossible when discussing them with the PPG during the first follow-up meeting, 1 month before the national lock-down.

6.6 Discussion

6.6.1 Summary

The intervention enabled patients and staff to work together to agree attributes to include in a survey, distribute the survey, and agree action plans which included patient centred service improvements. Meetings to agree attributes used in the local surveys (M1a, M1b, M2) allowed patients to share their experiential knowledge of the service, and staff to share their practical knowledge of previous service improvement attempts through deliberation. The exchange of knowledge in the voting meeting (M2) resulted in all participants changing at least one of their votes, sometimes in favour of patient preferences and sometimes in favour of staff preferences. Both practices were able to distribute the survey and there were advantages of using all three survey formats. Survey responders were different to the practice profile, but where the PPG patients helped to distribute the paper survey, this resulted in a more diverse sample. In Practice 1 the most important attribute was ‘*being listened to*’. This survey produced clear, statistically significant results that were in the expected direction, suggesting internal validity. In Practice 2 the most important attributes were ‘*appointment length*’ and the ‘*doctor knowing your medical history*’. This survey produced less clear results, which were not always in the expected direction or statistically significant, suggesting limited internal validity. Patients and staff rated the success of the survey based on the response rate, rather than the results, which they found difficult to interpret. Both patients and staff contributed to creating the action plans (M3). Action plans arose from a combination of the results of the DCE, the free text comments, and existing practice or individuals’ priorities. Patient influence was derived indirectly through completing the survey (DCE and free text comments), and perhaps more significantly, directly through deliberation in the voting and action planning meetings.

6.6.2 Comparison with the patient involvement literature

Our intervention has a number of similarities with other interventions aiming to increase patient involvement in health policy and organisational decision making. The intervention meetings resulted in patients influencing decisions about which attributes to include in the survey (M2), and the content of the action plans (M3). Boivin et al suggest that for meaningful involvement the public need to have credible knowledge, representational legitimacy, and facilitated power within meetings.(101, 102) The attributes were seen as relevant and credible, and the card sort exercise (M1a/b) and voting meeting (M2) allowed two way deliberation and exchange of patient experiential knowledge and staff practical knowledge. Boivin found that patient centred indicators were prioritised when the public was involved.(101) We found everyone in the voting meeting changed their votes after deliberation and knowledge exchange. This happened before the *consultation* intervention components (the prioritisation survey) which attempted to address statistical representational legitimacy, suggesting this element may be less important than previously thought. LaNoue et al employed concept mapping to involve patients in decisions, but adapted this to address representational legitimacy by increasing the number of patients involved.(99) Haesebaert et al use an action research process of facilitated meetings focused on brainstorming and then ranking.(100) This is a similar process to our action planning meeting (M3). In both cases patients were able to influence service improvement priorities. However, Haesebaert reports that patients and staff were very concerned about representational deficit, and we found patients struggled with the card sort meeting and the idea of making decisions on others' behalf.(100) This is not surprising considering that focus groups with patients who had never heard about patient participation, questioned the democratic legitimacy of who was involved and had power to suggest what was improved.(251) Patients in Haesebaert's study suggested collecting survey data to overcome their representational deficit, whereas patients in our intervention appeared confident making suggestions in the action planning meeting, possibly due to the ability to base actions on the survey results.(100) This supports Boivin's assertion that representational legitimacy is important, and combining two mechanisms of participation, *partnership working* (meetings) and *consultation* (the prioritisation survey), may have more impact than patient involvement in meetings alone.(102)

The intervention was successful in that two surveys were produced and enough data was collected to allow analysis and statistically significant results. Both surveys had relatively short data collection periods. Despite this, the overall sample size was greater than recent waiting room patient experience surveys.(247) This was partly due to the different modes of survey completion. Ong and Saunders explored different modes of completion, particularly digital modes, in hospital and general practice waiting rooms.(252) They discovered different barriers to data collection related to patient characteristics: physical barriers were prominent in the rheumatology clinic, and privacy issues in the mental health setting. They warn that mode of survey completion is important to consider as it may exacerbate inequalities, reinforcing barriers to feedback for those with the most need of service improvement.(252) Carter also expressed limitations of digital feedback modes which exclude the elderly, and those with poor literacy or English as a second language.(253) These inequalities in data collection were observed with our survey, especially regarding literacy. However, similar to other studies we found response rate increased when staff or a patient volunteers prompted and or helped with the survey.(247, 254, 255) Ong et al coincidentally recruited a practice with a PPG who took on the role of assisting patients completing the survey in the waiting room and this had a significant impact on the success of implementation.(255) This reinforces our findings that data collection is a valid role for a PPG. The fact that a more diverse population was sampled by the patient volunteers supporting the paper mode of survey completion in our study needs further exploration. Another positive of our intervention was the speed of presentation of the results. Carter piloted real time patient feedback in general practice and found that timely feedback increased staff engagement.(253)

Despite the apparent success of the intervention meetings and survey data collection, action plans were only loosely based on the results of the survey. This raises the possibility that our intervention focuses on data collection rather than action, similar to other interventions aiming to promote service improvement based on patient feedback.(81, 84-86) Success of the survey in our intervention was judged by participants based on quantity of responses not the results of the survey and how usable they were. Farrington et al describe how doctors want to use patient feedback, but are concerned about patient subjectivity and the scientific validity of the survey.(89) Sheard et al also discuss this as a barrier to staff utilisation of patient feedback and describe this as normative legitimacy. They also observed other barriers to the use of feedback including structural legitimacy (belief they have the agency and resources to affect change), and organisational readiness.(256) Their findings stem from a process evaluation of a trial to improve patient safety through facilitating staff action research groups to act on patient reported safety issues. The trial showed no impact, and in a linked paper they describe this as being due to considerable variation in the context and engagement of participants.(27, 257) The trial action plans were not solely based on the patient data and often depended on: existing priorities imposed by the senior hospital management, whether or not interaction with other wards and departments was needed, and complex interpersonal relationships and individual priorities.(27) This is similar to our intervention where the action plans included personal and practice priorities that were not specified in the survey results. However, there were also examples of the free text data being used rather than the DCE results, and all participants contributing ideas. Qualitative data such as this has been described as “soft intelligence”.(258) It has been suggested that this data is vitally important to the early recognition and prevention of poor care, but that it is difficult to capture, interpret, and use. Equally, Burns argues that rather than seeking consensus about the priorities, change should focus on issues which resonate.(143) Both these arguments suggest that it is acceptable to generate and implement action plans which are based on soft intelligence and resonate with the stakeholders involved. Other researchers suggest the utilisation of patient feedback depends on team dynamics, including different forms of social capital, and that patient involvement may extend the social capital within the team.(84, 85, 253) What is clear, is that the production of a negotiated action plan developed by a team, requires facilitation to address equity of voice, which will be discussed further in Chapter 7.(100, 102, 259)

Although shared decision making is not the primary focus of this thesis, both participatory mechanisms of our intervention include components similar to those identified as essential for individual shared decision making. These include, but are not limited to: creating choice awareness, information sharing, and elicitation of values and preferences, all through a deliberative approach.(260-263) The card sort in M1a and M1b create choice awareness, the exchange of information about different features of general practice, and opportunities for intra-stakeholder values deliberation. The voting in M2 enabled patients and staff to build on information sharing and focused on exchanging values and preferences between stakeholder groups through deliberation. The survey explicitly created awareness of choice within the wider patient population, provided information about different features that could change, and asked respondents to consider what they value. It could be argued that patient experience surveys help respondents to think about what they value, but do not create awareness that a choice exists or provide information on the different choice options. In other settings, parent-child dyads completing prioritisation surveys together, valued the opportunity to deliberate independently from the outcome of the survey.(197) Opportunities to share values between stakeholders, deliberate, and understand how and why different stakeholders make certain decisions, are therefore an important outcomes of the intervention irrespective of the result of the survey or outcome of the action plan.

6.6.3 Comparison with DCE literature

It is good practice to compare the results of a DCE to previous DCEs as a way of checking validity.(235) This is difficult with general practice DCEs due to their diversity, the range of potential attributes and levels, and the framing of the choice task (see Chapter 4).(264) Kleij et al's systematic review categorised general practice attributes as those relating to structure (waiting time till appointment, choice of GP), process (shared decision making, length of consultation), or outcome (receiving the 'best' outcome). They found that overall patients' value process attributes most. This supports both Practice 1 and 2 surveys' reporting process attributes as the most valued. In our systematic review of DCEs (Chapter 4, section 4.4.1) we found one study where *'doctor listens'* was the most important attribute (220), and two where the most important attribute encompasses listening (*'being able to talk to the doctor'*).(223, 225) One study reported that the most valued attribute was *'see a person who has information about your medical history',*(224) and three studies where continuity of care was the most valued attribute.(217, 218, 230) The review in Chapter 4 identified appointment length as a frequently used attribute, as did the review by Kleij, but it was never the most valued attribute.(264) The commonest most valued attribute in our review was waiting time for an appointment.(119, 219, 221, 231, 233, 264) In the current study, patients in both practices were interested in this attribute in M1a and M2, but staff said it was impossible to change. This demonstrates the importance of who decides which attributes are used in the survey as a limitation of investigating patient preferences.

Our review of studies found that there was a strong respondent status quo bias, i.e. patients would prefer to stay with their current service rather than change the service.(226, 227) This is in keeping with our findings that respondents in both practices valued things staying the same, more than they valued attributes improving. The majority of studies in our review also reported preference differences based on demographic characteristics of the respondents.(264) In addition, three studies reported preference differences based on the type of appointment or symptom scenarios respondents were presented with in the choice task.(202, 221, 222, 224, 231) This suggests further subgroup analysis may explain the heterogeneity between respondents in Practice 2.

6.6.4 Limitations

This is the first attempt at using a DCE as a locally adaptable tool to stimulate service improvement. Research suggest locally adapted surveys, which are less emotive, may result in greater staff utilisation for service improvement.(89) However, a major limitation is the reliability and validity of the DCE. An essential foundation of participatory research is that the methods used are robust and trade-offs are not made between participation and scientific rigour.(19) I made the decision to maximise the sample size and produce results in time to fit in with existing meetings, at the expense of reliability and validity measures in the DCE (Table 4.8).(235) The survey in Practice 1 appears to have internal validity, but this is less clear for the survey in Practice 2. The sample size was too small for sub-group analysis and heterogeneity testing which might have explained the results in Practice 2, and resulted in a better model. However, without further reliability and validity measures, it is difficult to assess whether there are significant concerns about the data quality. Therefore we cannot comprehensively conclude whether a DCE is a valid method for collecting local patient preferences for service improvement. In contrast, it appears to be a good enough method, within the wider intervention, to stimulate change.

A key step in designing a DCE is conceptualising the choice process (Chapter 4, Section 4.3).(199) We wanted to develop a flexible prioritisation survey recognising the considerable variation that exists between each general practice organisation.(144) This appears to be justified as there was no overlap in the attributes the two practices chose to go in their survey. However, as a result some key steps in the DCE design process were minimised.(199) Although we piloted all the 24 attributes and levels to test if respondents understood them (Chapter 4), we did not pilot to see if the attributes interacted with each other. The unclear result in Practice 2 may be partly due to interactions between attributes: *'choice of doctor'* and *'continuity of medical history'*; and *'support to manage your health*' and *'advice about community groups and lifestyle activities*'.(199) In future implementation, ideally PPGs would need advice on which attributes to avoid combining in order to have a valid instrument. This would involve further testing of the whole intervention, or adding a local pilot into the intervention process, which would increase the complexity of the process.

We originally chose a DCE as staff valued the idea of patients having to make trade-offs, and this helped recruit both intervention practices. However, in addition to the complexity issues described above, 10% of the patients disliked the survey enough to comment on it in Practice 1 (Table 6.16). These were difficult choices, which were framed as decisions on behalf of a population rather than an individual. This, and the increased number of actors involved, are key differences between organisational shared decision making, and shared decision making about individual care preferences. However, there are clearly some common components across both decision making contexts as discussed above, and the individual shared decision making literature may help to explain the high level of dissatisfaction with the survey.(260-263) Individual shared decision making evidence demonstrates difficult choices are cognitively challenging and elicit negative emotions.(263) However, people are happier with their decision if they have been supported to consider all their options, their values, and the negative emotions associated with the decision and decision making.(262, 263) Therefore dissatisfaction with the survey may actually be an expression about the difficulty of the decision, and negative emotions may suggest success in engaging respondents in the decision making process. This has potential implications regarding supporting patients and staff when making difficult decisions about organisational change. There are also significant concerns about the literacy level and cognitive burden required to complete the survey, with both surveys oversampling university educated responders. This suggests it may be worth exploring other methods of collecting local patient population preference data. There are increasing calls for utilisation of qualitative data, and this was used in both action plans, and text mining software is increasingly sophisticated to help with analysis and reduce burden.(84, 265)

Equally, simpler preference elicitation methods, such as best-worst scaling or participatory ranking methods might be easier and more sustainable to use.(151, 184, 266)

Finally, we only tested the intervention in two general practices due to pragmatic reasons and the complexity of the intervention. Sheard et al suggest their intervention did not produce significant trial results due to varying levels of engagement due to contextual factors.(27, 257) The intervention was designed to be flexible taking into account general practice variation. However, we did struggle to recruit a second practice and this suggests that engagement may be a problem when scaling up the intervention. Our data collection regarding implementation of the action plans in Practice 2 was curtailed due to Covid-19. Hospital based interventions have shown that even when action plans are developed they are not always implemented for a number of reasons.(27, 85, 256) Practice 1 had implemented or started to implement all their actions. The action plan in Practice 2 had more personally held priorities that were less related to the survey results. It would have been interesting to observe whether this affected implementation. Further testing of the intervention should include a longer follow up to see whether actions are implemented and what happens next.

6.6.5 Conclusions

The intervention succeeded in involving patients in service improvement priority setting in both intervention practices. Intervention meetings enabled two way credible knowledge exchange between patients and staff, resulting in both patients and staff changing their priorities. The prioritisation survey provided indirect involvement through consultation, increasing the number of voices involved, and helping to address some concerns about representational legitimacy. Facilitation of meetings and participatory methods ensured all participants contributed to the action plans. Action plans were not always based on survey data, but as patients were present in meetings, these were still heavily patient influenced. This suggests an interdependent relationship between the representational legitimacy of the survey, and the symbolic participation of individual patients within meetings, in order to achieve influence. The intervention, *partnership working* (meetings and generation of an action plan) and *consultation* (survey distribution) was feasible, but there are still questions about whether a DCE is the best method for surveying local patient population priorities. There is also ongoing uncertainty about whether the intervention results in the implementation of patient centred service improvement, and whether the intervention normalises patient participation. This last issue will be considered next in chapter 7.

7. Field testing results: Co-research group level of inquiry

This chapter describes the qualitative evaluation of the intervention. **I will synthesise the learning regarding the work required by both PPG members and staff in the two PPGs field testing the intervention to achieve meaningfully patient participation in general practice service improvement.** The analysis demonstrates that to achieve meaningful patient participation, actors (PPG members and staff) must work to create and maintain an inclusive, equitable, and safe participatory space. The data describes the work actors need to invest in to create and maintain this space, how our intervention facilitated this work, and why the space was not completely sustained beyond the lifetime of the research. From this, we have developed a framework of the work required to create and maintain participatory space. This can be used to strengthen our intervention before further testing, and may be useful in the design and evaluation of other participatory spaces.

7.1 Introduction

Throughout the thesis, I have used Normalisation Process Theory (NPT) as an analytical tool to clarify the work of participants in designing the intervention and implementing the intervention.(168) As discussed in Chapter 2 (Section 2.6) using an existing mid-level theory is an efficient way to understand a phenomenon. During the field testing, NPT aided clarification of the intervention, by focusing on "***what is the work?***" p549 (168). This project is primarily interested in the practice of meaningful *partnership working* to share organisational decision making between patients and staff in general practice PPGs. Therefore we are interested in **the work of meaningful partnership working**. This suggests that while what they work on together (sharing decisions to adapt and distribute the survey, and developing an action plan) is important, even more important is **what work they invest to develop and maintain relationships**. It is here that the concept of *participatory space* is useful, as Cornwall argues that creating participatory space is the essential pre-condition for partnership working and shared decision making.(50) Therefore, in response to "what is the work?", the answer is **the work of creating and maintaining a participatory space.** As discussed in Chapter 1 space is created and maintained through complex social processes.(50, 57) Space has properties which are physical, social, and temporal. Spaces are flexible and may change in size, shape, and composition over time. Social norms exist regarding the purpose of a space and how it is used, but these are often tacitly understood with fluid boundaries in contrast to organisations which have formal rules and regulations. Spaces are influenced by their history and other spaces with which they interact. Spaces are intertwined with relationships, and relationships cannot exist outside the space in which they are *“lived, experienced, and practiced”.(50)* Participatory spaces take multiple forms (see Chapter 1). **Through developing the intervention with the co-research group (CRG), we define an ideal participatory space as one that is inclusive, equitable, safe, and allows the exchange of different forms of knowledge through deliberation. Creating and maintaining a space, or changing space, is dependent on actors exerting effort, and therefore can be conceptualised as a practice requiring work.**

Cornwall alludes to the literature on participation which focuses on “*methods and mechanisms and how they are supposed to work*.”(50) This literature has been supplemented since then by the predominance of case studies and toolkits of participation, with some literature focusing on the purpose of participatory space.(37, 54, 99, 267-270) Cornwall calls for research that focuses on *what actually happens in these spaces*, and *how these spaces interact with other spaces*.(50) Therefore this chapter explores the work required to create and maintain a participatory space within PPGs. We focus on the work needed to create the space, the boundaries of this space, the interactions with other spaces, the role of agency influencing who can affect change in the space, and how the space changes overtime from the pre-intervention, to intervention, to post intervention space. The data presented in this chapter is from the observations, documentary analysis, and interviews collected during field testing the intervention and described in Chapter 5.

7.2 Results

Fourteen participants agreed to be interviewed following all intervention meetings and at least one follow up meeting. Table 7.1 outlines the roles of these participants, characteristics have been omitted for reasons of anonymity. Tables of all participants are available in Chapter 6 (Tables 6.2 and 6.3). In each practice there were unique factors and challenges that promoted and inhibited the work to create a participatory space. Despite this, through the use of NPT we identified similarities about the component mechanisms of the work that occurred, or did not occur, and the impact this had on whether or not the space changed and was maintained.(168) Four themes, related to the component mechanisms of NPT, will be discussed: understanding the space (coherence), committing to the space (cognitive participation), working within the space (collective action), and appraising the space (reflexive monitoring).

Interview quotes are identified by the practice number and then participant number. For example P1P4 is Practice 1, participant 4. Quotes from observational notes are identified in full. Where quotes have been altered for clarity, brevity, or anonymity, alterations are signified by square brackets []. In this chapter I refer to participants as actors to highlight their active role in the work.

Table 7.1. Roles and identifiers of interviewees

Practice 1		Practice 2	
Identifier	Role	Identifier	Role
P1P1	Engagement Lead	P2P1	Patient
P1P4	Patient	P2P2	Patient
P1P12	GP Partner	P2P3	Patient
P1P13	Patient	P2P5	Reception Manager
P1P14	Practice Manager	P2P7	Practice Manager
P1P18	Patient	P2P13	Salaried GP
P1P20	Patient	P2P15	Patient

7.2.1 Understanding the space

Creating and maintaining a participatory space requires all actors to invest effort in defining the space, recognising the roles and behaviours necessary to organise the space, and valuing the space.

Defining the space involved working to understand how it is different to other spaces (differentiation), particularly the pre-intervention PPG space, and how and why this space was valued (internalisation). Both PPGs had existed for a number of years (P1=13 years, P2=7 years) and had been established by the staff, but there were very different meanings of the space. Practice 1 staff saw the space as an extension of their practice philosophy of being patient centred.

> *"*[The Practice] *belongs to the patients. It's their practice. It has to meet their needs. And if we don't have a way of understanding whether it is or isn't meeting their needs* […] *how can we possibly effectively achieve that?"* P1P12 (GP partner)

Practice 2 staff established the PPG in response to contract changes and it has practical value in meeting their contractual obligations. They see the space as a patient space, where patients do the work, which is additional to, but separate from the practice.

In both practices, some staff internalised the space as having value or not depending on whether the space inferred value on their roles within the practice organisation:

> *"I think it's really important for the Practice Manager to be in touch with what patients are feeling and thinking about the service. Em and as I'm, my daily job doesn't bring me into loads of direct contact with them em then I need to avail myself of the opportunities that there are and the patient group is one of them."* P1P14 (Practice Manager)

However, a GP partner in Practice 2 described the group as having no value, as meetings involved:

> *Going along and being asked to do things by patients who had unrealistic expectations of what is possible.* Practice 2: Notes of meeting with Practice Manager and GP Partner.

These examples show the overlap with, and influence of the participatory space on the practice organisation space and vice versa. PPGs are promoted as participatory space where decision making occurs, but decisions about the practice are often taken elsewhere as well.

In both practices the PPG members understanding of the pre-intervention space was very different to the staff. In Practice 1, PPG members were invited to the space without knowing anything about it.

> *"*[The GP who suggested the group] *didn't explain much about it. And what, I remember going to the first meeting … and not … coming away from it not … knowing very much more than when I … first went there!"* P1P20 (Patient PPG member)

They continued in the space to find out information about the practice, to feedback individual issues, and to support the practice in their role of being a good patient. PPG members in Practice 2 saw the space as an opportunity to work with the practice to improve patient care. They felt their ability to achieve this purpose was frustrated by the practice who mainly had a group because of the contract.

> *"I do feel that the* [Practice Manager] *has always thought well we've been told we have to have one of these, so we have it, but we're not really interested in what they talk about. We always felt side-lined and I think since the survey, it's been brought to his attention that we are more useful than he thought we were."* P2P2 (Patient PPG member)

In both practices there was little evidence of communal specification work which involves having a shared understanding about their work. Both had longstanding terms of reference, but these were not discussed or referred to in either practice during the research. Equally there was little evidence of PPG members and staff doing any work to collectively understand their different perspectives on the meaning of the space. In Practice 1 this led to PPG members considering leaving the space as they had no agency to affect the meaning.

> *"I just gave up going.* […] *Because I didn't like the set-up. And I didn't feel I was getting anything out of it. And I didn't feel I was particularly … very able to put anything into it.* […] *I thought shall I … say something about it? And then I just thought no! I'm not going to, I'm not going to bother. I'm not that interested really."* P1P20 (Patient PPG member)

In Practice 2, this led to conflict between the PPG members and staff about the meaning of the space and the work within the space.

> *"The way it runs, erm there has been some tension between erm staff and patients in the past, er one of the main areas of contention was the remit of the patient group and er* [the Practice Manager]*'s view on what the patient groups remit was, was slightly different to ours, er he saw it as a, a body that amongst other things is there to provoke the practice, we said most definitely it isn't, erm and we had a bit of tension"* P2P1 (Patient PPG member)

Our intervention aimed to clarify the meaning of the PPG as a space for partnership working. Therefore the CRG contributed to the work of communal specification, by outlining the intervention. However, we found that the work of individual specification and internalisation were more important for ownership and lasting change.

Individual specification of the space and actors roles within it developed by spending time in the space and engaging in the collective action within the space (Section 7.2.3). In both practices this resulted in valuing the space. In Practice 1 the PPG members developed their roles and responsibilities as they started to understand the space was somewhere they could make a difference.

> *"Oh we'll continue with that* [waiting room listening exercise] *'cos we like it. And we feel it's important. And as I say* [Practice Manger] *said when we get feedback, then she'll do this, "right you've said this, right we've done such and such!" So we can see an outcome really. We've asked a question. There's the feedback and there's the outcome."* P1P20 (Patient PPG member)

In Practice 2 intervention meetings were seen as constructive by both PPG members and staff, and this led to staff sharing their knowledge and valuing the patient contribution.

In both practices, patients who were new to the PPG space or had not attended intervention meetings, appeared to struggle understanding the intervention space. In Practice 1, PPG members who only attended the results meeting, focused on giving critical feedback which had been their role in the pre-intervention space. The GP felt this was because these PPG members had not invested the same meaning in the process.

> *"So then there were lots of people who were in that meeting who hadn't been at all the previous meetings. And I felt like that was probably the biggest challenge of the meeting.* […] *I wondered whether it was the best meeting for people who'd not been involved at all to come to?"* P1P12 (GP Partner)

Similarly, in Practice 2 the Practice Manager worried that the new person at the results meeting had misunderstood the space as a complaints forum.

> *"[T]hat patient, by her own admission on the day, came expecting to come with complaints and issues and concerns, rather than get involved in a, in a project of how we can collaborate with each other"* P2P7 (Practice Manager)

None of the actors made any attempt to explain the meaning of the new intervention space to returning or new actors.

Our intervention focused on achieving communal specification. However, meaning making was an ongoing negotiation over time within the space. Resources (time and deliberation) need to be invested in this negotiation process on an ongoing basis to achieve lasting change in the space, especially when the space is fluid to changing membership. All this demonstrates that all actors need to work to understand the space. The work of understanding and valuing the space depended on how committed people are to the space.

7.2.2 Committing to the space

Creating and maintaining a participatory space requires all actors to invest effort in committing to the space. This raises questions about who is or is not invited into the space (legitimacy), and by whom (initiation), and how (activation) and why (enrolment) do people commit to the space.

Both PPGs are what Cornwall describes as invited spaces.(50) The meetings are held on practice premises and PPG members are required to sign in at reception. The initiation work was done by the practice, after they had developed an understanding of the space. PPG members had little idea of why or how they had been chosen, sometimes years previously.

The inviting work required effort. At the superficial level, the invitation to the physical meeting provides legitimacy for patients to attend meetings. In turn, patients attending meetings provides the practice with a legitimate way of meeting their contractual requirements. In Practice 1, staff, mainly the Engagement Lead, were involved in an ongoing and active non-systematic recruitment process. In Practice 2, active recruitment had not occurred for a while. Staff had given up inviting patients, as they perceived they had a sufficiently large group, and had previously struggled to recruit patients, which they blamed on the demographics of their population.

> "[W]*e made several attempts to get a patient group going and it was exceptionally difficult here,* […] *a lot of it can be down to the demographic, there is…there is general apathy of course as well, erm but I think it's down to the demographic, I mean, we can have anywhere between forty seven and sixty seven languages in the practice, and I think a lot are reluctant erm to take part"* P2P5 (Reception Manager)

One aim of the prioritisation survey was to give PPG members the role and opportunity to invite other patients to the PPG space, aiming to increase the representativeness of the PPG.

This appeared to have limited success: four new patients joining meetings in Practice 1, and three new patients expressing interest and one joining one meeting in Practice 2.

Cognitively engaging people in the space required more effort than getting people to attend the physical meeting space. This required investing meaning, feeling safe, and feeling legitimate. Feeling safe was closely associated with feeling legitimate. All actors invested relational effort in their real and perceived legitimacy within the space. Believing they were legitimate depended how they perceived others judged their legitimacy, both PPG members and staff, and whether the work in the space was perceived as legitimate.

PPG members' behaviour toward each other had a significant impact on whether they believed they were legitimate. In Practice 2, one PPG member was sometimes confrontational in meetings, she often interrupted people and shouted at another patient, P14, in the follow up meeting. Over time we observed P14 slowly withdrawing from the space. In Practice 1, PPG members described this type of behaviour from other PPG members as excluding them. These internal views about their legitimacy to other PPG members were influenced by social norms, including structural racism.

> *"I didn't like it* [the pre-intervention space]*! I felt there were a lot of dominant voices and that it just didn't suit me. So I kind of came to two and I didn't come back!* […] *They were white middle class voices whose voices always gets heard.* […] *I just didn't like it and they were not very … they would be a bit derisive about what people said and there were just the same people! Not my type of people,* […] *I didn't feel it was … representative much as well. And … and, and the reason why I have to put a caveat to that, I think that a lot of the time my black friends … don't go to things. "I'm not going!" And they'll say all kinds of things but what it really is, "I don't feel confident to go! I don't feel I have a space in that room." And they don't go.* […] *They make all excuses! So that's not to say that the practice wasn't trying to be inclusive… but you, you get a proportion of people of colour often that feel … em … don't feel good in certain spaces."* P1P18 (Patient PPG member)

Facilitation, particularly by a person of colour from the CRG, and intervention meeting warm up exercises focusing on establishing relationships between PPG members, helped overcome some of these barriers.

PPG members sought active expressions of staff believing they were legitimate, such as getting support for volunteering activities. PPG members perceived the meetings, and hence their role as more legitimate if staff, especially GPs attended them. PPG members' desire for staff to attend meetings appeared to relate to their status as well as their specific knowledge.

> *"I just, I just feel that em the way that* [the Practice Manager] *in, involved himself … em … was em … I just, I thought that was, yes, such a breakthrough.* […] *and also one of*

> […] *the, the … one of the doctors came. Em … and, and I, I … that was good. That was good."* P2P3 (Patient PPG member)

However, some GPs perceived the space as an illegitimate use of their time based on the socio-economic and cultural status of the patients.

> *The GP Partner said that he did not think it was a good use of his time meeting with this group of people. He said that they were only a small number of white, middle class people, who didn't understand or represent the majority of patients at his practice.* Practice 2: Notes of meeting with Practice Manager and GP Partner.

Nevertheless, staff who spent time in the space, valued the space and the PPG members within it, which conferred status on them. This status separated the PPG members from the rest of the patient population. In Practice 2, it transpired that the PPG members received easier access to online services because they were known to staff. This had the effect of delegitimising the PPG members' knowledge of the system, as their experiential knowledge was based on preferential treatment.

Inviting other staff into the space, and their enthusiasm for the space, conferred legitimacy on the space and the roles of the key staff in working in the space. In both practices the staff card sort meeting emerged as a whole practice meeting. This meeting raised awareness of the project and the PPG within the practice space. Staff were engaged in the topic and committed to change, because they were accountable to the PPG.

> *"They know that there's a PPG discussion and … em … we talk about it at our weekly meeting but the … in terms of the team themselves, they're just busy getting on with what they're doing. So they don't really … take the time to, to understand or think about what the PPG were doing. So the fact that we did that group session, it opened the eyes of everybody to understand what the PPG actually do and em who they are and the thoughts and the ideas that they're coming up with."* P2P7 (Practice Manager)

The intervention provided both PPG members and staff with legitimate and credible work to do within the meetings. The survey features were seen as legitimate by both PPG members and staff, especially the focus on changes which could potentially be implemented.

> *"It was good because … dealing with issues in which … there are limited em … options … if you … if you make it too open … you can get a lot of … a lot of different ideas but they're impractical. They can't be implemented… By … focusing it in the way that em … yeah focusing it the way that I think … help … helped everybody to get down to … choosing what they … what could be practically implemented."* P1P13 (Patient PPG member)

PPG members found the card sort meeting difficult, as they did not always feel it was legitimate to ask them to make decisions as a representative for the whole population.

> *"I think most people don't really know how to do it* [represent more than their own opinion]*. They're don't, they're not used to it. It, cos often they're asked their opinion. And that's it. And so thinking of, yeah I do have an opinion cos I'm a patient but we're also trying to represent the wider em … surgery, surgery population. It's not a usual thing. So people struggle with it."* P1P18 (Patient PPG member)

PPG members accepted doing this work because it was seen as part of a process to develop a survey that would give the wider population an opportunity to express their opinions too.

Legitimacy activated the space and encouraged PPG members to take on new roles and responsibilities. PPG members in Practice 1 took on more roles and responsibility after they were given explicit permission by the Practice Manager.

> [The Practice Manager] *turned to the group and said "I'd find it useful if we could talk about how this group hold us to account".* […] [She] *then explained that she is always really busy and things get done when they are at the top of her priority list.* […] *She then said "I'd like this group to be more assertive". This massively opens up the group discussion and gives permission to the group members to speak up. Immediately, P1P20 suggests that there should be different leads for different activities within the group.* Practice 1. Notes from first follow up meeting

This permission conferred legitimacy on the space and PPG member participation in it.

Doing work increased PPG members' legitimacy in the eyes of the staff as it added value to the practice. If this work was recognised, PPG members' perceived legitimacy and engagement in the space increased. This built mutual respect, and signified a shift away from discussions of legitimacy based on representativeness. This demonstrates that the work of understanding the space, and committing to the space are interconnected with the work done in the space and the work of building relationships.

7.2.3 Working in the space

The space would not exist without actors within it, but the relationship(s) between the actors defines the space. Therefore, operationalising the space requires work within the space to construct meaningful relationships based on trust and mutual respect. Trusting relationships are those which are safe enough to allow challenge. Mutual respect requires equity of voice and valued knowledge exchange. Relationship building is a social process which develops over time within the space. We observed that relationship building work was rarely explicit. Actors needed a credible and legitimate task, focused on action, to work on together, to allow tacit relationship work to occur. The practice staff were engaged by their interest in the trade off aspect of the survey. PPG members were motivated because they took on roles that were active. This contrasted with descriptions of pre-intervention meetings described by many actors as a "*talking shop*" and being just about "*politics*".

The prioritisation survey task provided the opportunity to introduce participatory methods and facilitation. We observed trust and mutual respect developing over time in both practices. Facilitation work was enacted by the CRG understanding the existing relationships, and tailoring meetings to promote welcoming and inclusive practice.

> *"I kind of grew more confident I think in the meetings with Jess* […] *and yourself* […] *I think part of it was that … Jess went round everybody. And she was very … keen to try and remember people's names … and she was also … very keen to make people feel that their ideas … and participation were valued as well."* P1P20 (Patient PPG member)

In Practice 1, none of the PPG members knew each other within or outside the meeting space, therefore facilitation focused on developing relationships between PPG members using a variety of warm up exercises.

> *"What our motivations were for being there.* […] *Were really important to hear. And everyone had different reasons why and different experiences. Em … and skills and stuff. So it was good to know and then sometimes if we found it difficult to make a decision you could think to yourself "oh that person, that's why they're coming from that because they've experienced that!" All of that's important I think."* P1P18 (Patient PPG member)

In Practice 2 a lot of the facilitation work happened outside meetings and focused on encouraging participants to overcome previous judgements between PPG members and staff.

The participatory methods structured the space to provide equity of voice for both PPG members and staff.

> *"Everybody around the table was asked … their views and that's quite … different to … how it was when I went to previous meetings. Where people were just shouting randomly and if your voice happened to not be a very loud one … then you might not get heard."* P1P20 (Patient PPG member)
>
> *"How much is, is my opinion more important as a partner than somebody else's?* […] *and how we make sure … em … everyone's voice is heard? But I think by using em a whole range of participatory, or a range of participatory methods, most people's voices were heard? Em … yeah I thought that it worked well."* P1P12 (GP Partner)

This was most explicit in Meeting 2 when participatory voting was used. Staff in both practices expressed concerns prior to the meeting that there would be conflict. In Practice 2 this was extreme and the practice staff hatched a plan to ensure staff outnumbered PPG members so they could physically "*outvote*" the PPG members.

> *The right half of the circle was already filled with members of staff* […] *The body language of the staff was that they were a 'rent a mob' – all sitting together in a unified wall of staff. P2s body language was that she smelt a rat at that many staff being present rather than being positive about new staff being present.* […] *It felt quite*

> *adversarial and like a battle line had been drawn down the middle of the circle of chairs.* Practice 2: Notes from meeting 2

However, the participatory voting provided an opportunity for knowledge exchange of patients' experiences, and the practices agency to affect change. Staff in both practices were surprised that consensus was easily achieved through listening to each other.

> *"I thought 'well they're not going to think what we think'* [laughs] *you know, and it wasn't, you know, we reached very, very, very quickly I thought, a common denominator and it was the same thing* […] *and that was really, that was surprising to me, you know, and that was lovely. I was very pleased about that 'cause I thought, because then it became even more worthwhile because I thought 'they're the areas I know are an issue', and we can, we could exact real change on it, and I thought, you know, so that was good, whereas I thought you know, I had concerns that they were going to be so wildly differing and opposites, and what on earth was I going to do then."* P2P5 (Reception Manager)

As the work of planning the meetings was done by the CRG, it was not always recognised, and therefore internalised, as work that the group could continue to do without the CRG involvement.

To create and maintain the space, the actors in the space also needed to utilise skills including: communication skills (empathic listening, patience, and tolerance), volunteer support skills, and leadership skills. In both groups many of the PPG members and staff already had these skills which are a form of practical knowledge. However, skills were only visible when they were used, and they were only utilised when they were visible. In Practice 1, several PPG members displayed excellent communication skills when distributing the survey, and leadership skills during the card sort meeting. However, the Practice Manager did not observe these activities and therefore did not know they had the skills.

> *"*[Y]*ou've got the people that you've got!* […] *there might be some groups that have got … somebody on them who … because of their work experience or for whatever reason is going to say come on let's have an agenda, and I'm going to be chair, and what's happened to all these actions* [banging on the table]*? But that's not who we've got on our group! They're never going to say oh by the way we've forgotten to look at the minutes from the last meeting, and go through the actions."* P1P14 (Practice Manager)

The Engagement Lead in Practice 1 and the Reception Manager in Practice 2 both displayed volunteer support skills, supporting and encouraging PPG members to distribute the survey. However, neither recognised or valued these skills, and PPG members only recognised the skills when the members of staff were absent.

> *"I hadn't realised the numbers* [of surveys distributed] *had tailed off,* […] *Well the thing is I would ask, when they were leaving I'd say 'well when are you back in?'. Maybe*

> *(laughs) so maybe that was the thing, I can't say I was on the phone saying come in now, but when they'd finished, and they were going, or, I'd say 'oh when are you in next?', so maybe they, yeah, maybe they missed that, I don't know."* P2P5 (Reception Manager)

Space, and the relationships within it, are socially constructed over time. Time was a key resource for operationalising the space, but was in short supply for all actors. Whether limited time was recognised related to the status of actors. Therefore, it was recognised that GPs and managers had limited time, and how this was utilised affected internalised legitimacy of other actors.

> *"The staff really, we never really get to communicate with them at all, they're…they're always too busy, and we have an ongoing problem with the GPs who don't, I don't think they want to get involved, so they always use busyness as an excuse."* P2P2 (Patient PPG member)

This influenced the CRG as we limited the length of intervention meetings to ensure staff would attend. But this was often at the expense of time for enactment, most actors said meetings felt rushed, and reflexive monitoring (Section 7.2.4). Other actors' time was not recognised. In Practice 1, the Engagement Lead (P1P1) was not given any dedicated time to do the volunteer support work needed between meetings. This resulted in her not supporting PPG members' as she would like to:

> *"The other day I had …* [P1P13] *ringing me and he was talking about the* [community event]*. And then I've got* [P1P20] *ringing me and she wants to talk about … being … feedback in reception cos that's her interest and …* […] *So I feel like I, I don't know whether I've let* [P1P20] *down cos I've been concentrating on the* [community event]*."* P1P1 (Engagement Lead)

PPG members' time was discussed even more rarely, even though it had a significant effect on the enactment of the space in both practices. One PPG member discussed not wanting to take on more activities within the space for fear that it would take up all her time; another stopped attending meetings as she did not have time; and two PPG members stated their limited time as a factor in not handing out more surveys.

The context of the space in relation to other spaces also had an impact on the operationalisation of the space. One PPG member described some patients as deferential to doctors related to cultural beliefs and social norms regarding how you should behave towards doctors.

> *"You've got the thing with doctors* […] *and I'm generalising but … if I look back to my* [parents]*, first generation and sort of emigrated here. They have a lot of deference to doctors and clinical staff and then, 'oh yes sir'.* […] *They would think "oh I don't have a*

> *space in there!" It's for me to be … kind of em … talked to, instead of talked with!"* P1P18 (Patient PPG member)

This was demonstrated by one PPG member not chasing up the Practice Manager despite her explicit permission.

The practice space was very influential over the participatory space. Existing staff hierarchy and relationships were demonstrated by who was involved in the space, how they were involved, and how much agency they had over their involvement in the space. In Practice 1, the Engagement Lead had little agency over her workload, and this inhibited her ability to support the participatory space. In Practice 2 the admin team were co-opted into Meeting 2 to 'out-vote' the PPG members. However, this resulted in new relationships between the PPG members and the admin staff which continued outside the meeting space:

> *"*[I]*t was good to be able to talk to the receptionists when it was quiet* […] *and they were quite happy to say a few things that they wouldn't be able to say otherwise, not negative things at all but one or two quite interesting things."* P2P1 (Patient PPG member)

The co-opting of staff into the participatory space also had a positive effect on staff morale and therefore the practice space resulting in a commitment to change.

> *"For several weeks after the, that, that particular session* [Meeting 2]*, they* [the staff] *were commenting, saying you know they'd really enjoyed it. And they were surprised to hear that so and so had that problem. And then they, they were actually trying to come up with solutions as well. They were saying "you know so and so had that problem, what about we do this?" And it, it was just something that … I'd not seen much of prior to that.* […] *So em I think it was that purpose, there was a reason for this. And as a result something will happen because the PPG are involved and we're going to do it for … the benefit of the practice and the PPG."* P2P7 (Practice Manager)

Confidence in the participatory space was linked to activation of the space. The space was activated by having a credible and legitimate task to work on, clear roles and responsibilities, feeling legitimate, and visible investment in the space. The intervention activated the space between meetings in both practices. In Practice 1, visible work continued between follow up meetings by both PPG members and staff, and where this was adequately supported and tasks were achieved, it increased confidence in the space.

> *"*[The process has made me feel more] *confident! And I'm really enjoying it.* […] *I'm really enjoying it you know. And I wrote this big piece for the newsletter. But you know I enjoyed doing that."* P1P4 (Patient PPG member)

Equally in Practice 2, confidence in the space increased as the different stakeholders committed to the work with visible investment.

> "[Give] *me a little bit of time to think, I start getting really engaged and you know then start putting my own time and energy into something and then it becomes, I become part of it. And, I think that's what happened in the team here is that em … people took on… the, you know, the project and they started to engage with it and it became part of them. And then, that builds energy doesn't it? By the end of it? Em … the, the … I don't know you just get wrapped up in the idea."* P2P7 (Practice Manager)

The PPG members grew in confidence because the practice agreed to get involved in the project and put visible effort in, and a GP came to meetings. The PPG members taking on the role of distributing the survey in the waiting room increased the confidence of the Reception Manager that the PPG members could and would do more:

> *"*[T]*hey don't think they should take a lead on things, whereas I think they should, and I was going to use this as leverage to say well, look what happens when you do take a lead on things, we can exact change."* P2P5

This was a positive feedback loop with more confidence in the work, leading to greater commitment to the space, and more effort on the work. However, we also observed one negative feedback loop. The PPG members stopped distributing the survey when the Reception Manager went off sick, and they lost their support. In turn the Reception Manager lost confidence in the idea that the PPG members would take on work themselves.

In this way confidence is also linked to the work of reflexive monitoring. Visible investment in the work, led to more confidence in the space.

7.2.4 Appraising the space

Reflexive monitoring describes the work actors invest in the continuous formal and informal monitoring and evaluation of the participatory space.

The work of appraising the space was subjective and done individually and in private. All actors appraised the intervention space as fun, constructive and consensual.

> *"*[W]*hen it comes to the meetings and things, I enjoyed them. They were fun.* […] *I liked them. Em … even role play! I remember the role play and that's something that I've never ever done before that, not something that I think I'd choose to do, but I enjoyed it! It were good."* P1P1 (Engagement Lead)

> *"I think we worked pretty well. Yeah. We had a, you know, we, we have a good few laughs and I think that's always healthy. Em and it means that we're all comfortable."* P1P4 (Patient PPG member)

In Practice 2, both PPG members and staff described the intervention as a process of creating a space that had brought everyone together and improved working relationships.

> *"I think in the past, you'd always seen sort of the patient group as one thing and the surgery as something else, and I think for that project it wasn't, it was one thing*

> *together, we were all working for the same common aim and I felt that was better, I mean, you think you're doing it but you're not, until you're actually the physicality is, is that you were doing it for the same thing and I felt that it was far more inclusive for both parties."* P2P5 (Reception Manager)

> *"I think that the, the patients and the staff* […] *have moved closer together.* […] *Em and probably appreciate each other more.* […] *And that we know because of the project, that we can do things together.* […] *Em and that … we would, we can make a contribution, each, each can make a contribution."* P2P3 (Patient PPG member)

Individual positive appraisal of the intervention space helped actors recognise the work that they valued and wanted to invest in maintaining.

The intervention did not include the actors in a formal evaluation of the space or the relationships within the space. The work of creating and maintaining the space described previously was implicit and therefore not always explicitly recognised. Some of the actors reflected that they would have liked a more explicit discussion of the relationship building work and actors' skills:

> *"I think if you're thinking about skills in the group and how the group's formulated* […] *I think you need to have an overt discussion about that.* […] *I'm not sure that it's going to drop out.*[…] *I would have been quite happy if we'd had a discussion about that. You know, how does the group function* [at the end of the intervention]*? You know what have we learnt about how the groups function through this project. Do we want to change how the group functions?"* P1P14 (Practice Manager)

This was a missed opportunity for PPG members and staff to share what they valued about the new space and also make visible the CRG work of planning and facilitating the meetings.

Without formally recognising the work, it is not surprising that in both practices, to a degree, the space moved back to the pre-intervention space. In Practice 1, all elements of the ambitious action plan were implemented, but the Practice Manager regained control of the space. For her, the value of the project was having an action plan to improve the practice. Therefore she invested in the actions, rather than working on the space. She did not know that the PPG members perceived the space had changed and valued the new space, because it was not discussed. In the follow up meetings she slid back into her old role of efficient chair.

> *"I hadn't considered that one of the outcomes might be that we start running the group differently.* […] *I mean I can make sense now you've said it, but yeah, yeah, when I'm so busy sometimes things do need spelling out in words of one syllable!* […] *I guess I didn't hear that!"* P1P14 (Practice Manager)

Without the opportunity for equity of voice provided by the participatory methods, the PPG members also slid back into passive roles within meetings.

In Practice 2, there remained an ongoing tension about roles and responsibilities for work between meetings. This was exemplified by arguments about who was responsible for the noticeboard.

> *"*[The patients] *see it that that is our role to do, not their role to do, and it's not a case of saying right, I'm not going to do that with you and I'm not going to help you with it or whatever. So, so I don't, so it's a bit difficult, I don't know how I'm going to address that going forward, but they do have to, I mean am I wrong in saying this, am I wrong in thinking that they should have more autonomy to, you know, to actually, me to be able to push back things to them, to say no, you need to do that?"* P2P5 (Reception Manager)

Despite the tension, staff felt there had been a lasting change in the space.

> *"*[H]*istorically you know that, that's the way that we've been* [a certain amount of tension in the space] *and it, it was, maybe we just accept that as being the norm so didn't really spot … that there was anything there? Em could be? Yes. Although since then you know we, we've been… doing various separate emails and communications and getting involved em … just in separate conversations now. Rather than just having the monthly meeting where they come with their list of demands … we're now having active email chats and em … just generally doing things differently."* P2P7 (Practice Manager)

Appraisal led to attempts to reconfigure the space, but the ability to change the space depended on the actors' agency, the understanding of their roles, and their recognition of the work involved. In Practice 2, the PPG members discussed rebranding as "the patient and staff group" to reflect their understanding of the role of the group. This change was within their control, but they perceived their ability to influence staff to attend meetings was outside their control. The PPG members believed that my status as a doctor was the factor that influenced staff to attend meetings.

> *"*[I]*t was good to get staff involvement, you know, to get the staff buy in, erm and I said to Jess erm said to be honest, if, if you'd not been selling this in, I'm not sure what the reaction would've been, but when you've got erm a GP, you know, talking on the same level if you like, and it's almost like on the same class level, when you've got a GP erm having the conversation with them and it's a lot, their attitude was, was probably a bit different from say what a patient group wants to do this or, it became…it was just, it then became a lot easier to, to get the buy in."* P2P1 (Patient PPG member)

Equally, in Practice 1, PPG members and the Engagement Lead recognised the value of a patient only space during the intervention, but they did not feel they had the agency to influence the Practice Manager.

> *"With none of our staff there … they can come up with their own ideas as well, that they want to put to the practice. I don't know if that's something that* [the Practice Manager] *might be trying to avoid? I, I've no idea."* P1P1 (Engagement Lead)

In contrast, GPs and Practice Managers with considerable agency showed little commitment to reconfiguring the space. Staff in both practices reflected that they did not need ongoing external facilitation, as they had the facilitation and participatory methods skills to support the group. But these skills were not utilised before, during, or after the intervention. This related to the meaning of the space as a patient space and their lack of investment in the space more generally.

> *"*[W]*hat I don't want is the group to feel that we … we're running it. Which is probably why I've never really offered facilitation em skills in the past because … you know it, it's their group."* P2P7 (Practice Manager)

Therefore, the social status attached to the roles of PPG members and staff outside the space affected the actors' ability to maintain and improve the space.

Appraisal work was constantly happening in the space, it influenced how actors understood the meaning of the space, their engagement in the space, and the structure of relationships and enactment of work within the space. The lack of opportunities for communal appraisal of the space limited actors' ability to recognise and work around social and institutional norms which impacted on the space.

7.3 Discussion

7.3.1 Summary

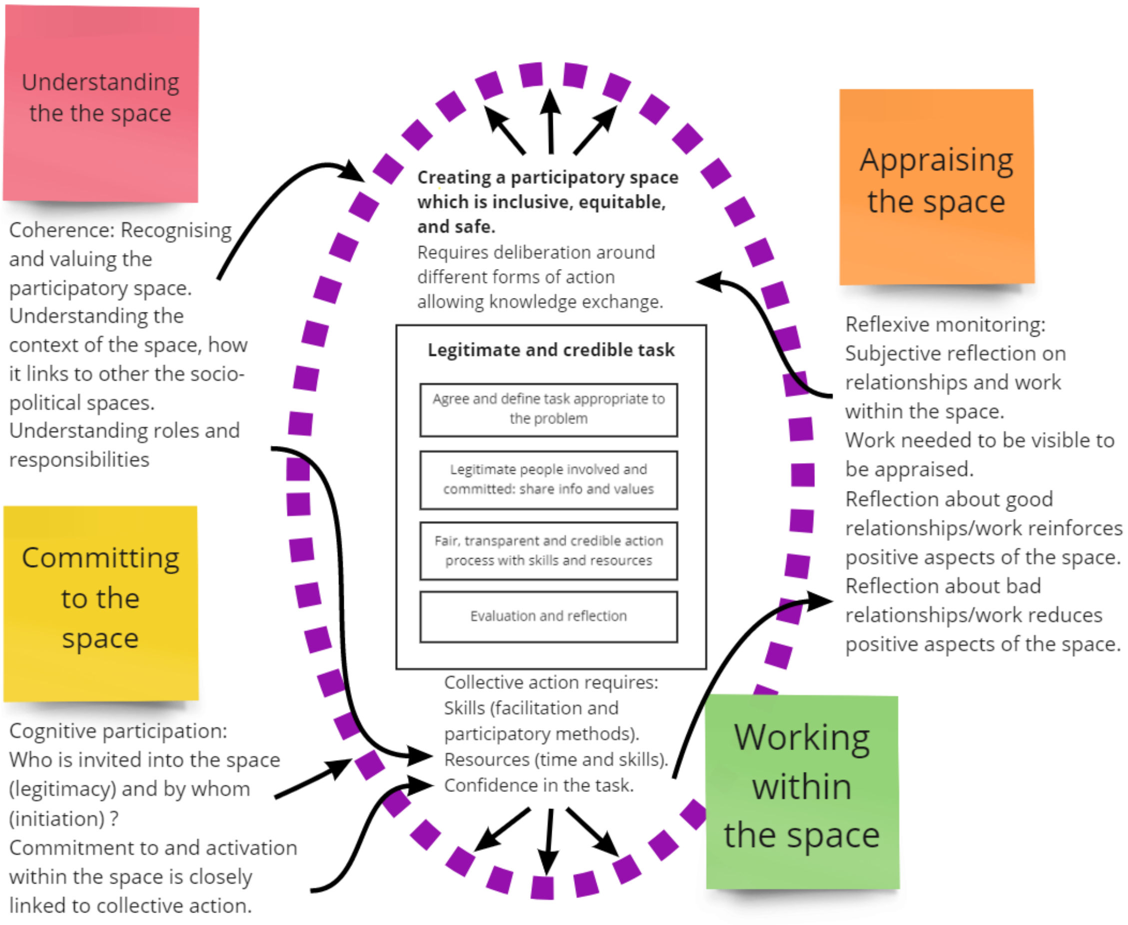
Field testing the intervention in two general practices demonstrates the work that actors need to do to create and maintain an inclusive, equitable, and safe participatory space. All actors both individually and collectively, need to invest effort: understanding the space, committing to the space, working in partnership within the space, and appraising the space. These four areas of work are interconnected and dependent on each other. Therefore, actors need to invest in all four areas concurrently and ongoing effort is required to maintain the space. The intervention and CRG facilitated the work of changing the space, providing meaning, a credible and legitimate task to structure the space, and facilitation skills and participatory methods to promote tacit relationship building. However, in both practices the space partially reverted back to the pre-intervention space when the CRG stopped facilitating meetings. The work of maintaining the space was inhibited by a lack of communal appraisal which failed to make the work of creating and maintaining the space visible and valuable to all actors, especially when there was fluid membership of the space. The work of creating and maintaining the space was influenced by other interconnected spaces, most notably the practice space and social norms in wider society. These external spaces influenced actors' agency to create and maintain the participatory space. However, we also observed the participatory space influencing the practice space, opening up possibilities for future patient influence.

The original intervention was based on three theoretical constructs required for patient influence in service improvement decision making (Chapter 3):

- All stakeholders have multiple **credible and different knowledge** to contribute. All different forms of knowledge (experiential, presentational, propositional and practical) are valued.
- All stakeholders have **legitimate roles**. Representational legitimacy of patients and staff is increased through different approaches to representation (statistical, democratic, and symbolic) and a focus on inclusivity.
- **Power differentials** exist within and between different stakeholder groups. Deliberative partnership meetings should aim for equity of voice.

These three constructs focused on stimulating action, and not directly on creating space. The actions included: partnership working in meetings to adapt the survey and develop action plans, distributing the survey, and implementing the action plan. As described in this chapter and Chapter 6 these actions, or tasks, were seen as credible and legitimate, especially when structured using participatory methods. The three constructs helped PPG members and staff share organisational decisions around one project, but other work was required for lasting change and patient participation in future projects. The credible task provided a legitimate reason for actors to come together and deliberate with a clear focus on concrete action and change. This created the opportunity to work to create a new participatory space which was respectful of different forms of knowledge, inclusive of all people, and valued equity of voice. Cornwall describes participatory space as a prerequisite for partnership working and shared decision making.(50) This project suggests the action and the space are inseparable. Without the space bringing actors together the action of working in partnership would not occur. Without the action there is no opportunity for actors to create the space, and the inclusive, equitable, and safe participatory space cannot be realised. The framework below demonstrates the relationship between the action (the task) and the work to create the space (Figure 7.1).

Figure 7.1. A framework of the work required to create and maintain a participatory space



7.3.2 Comparison with literature

The framework in Figure 7.1 draws on the four component mechanisms that actors need to adopt to embed a new practice outlined in NPT.(168) These four mechanisms are coherence (the work of investing meaning in a practice), cognitive participation (the work of committing to a practice), collective action (the work or effort of enacting a practice), and reflexive monitoring (the work of appraising a practice) (see Section 2.7 for more detail). Conceptualising the creation and maintenance of participatory space as a practice, allowed the analysis to focus on the wider, more implicit work that PPG members and staff must invest in as a precondition to partnership working and shared decision making.

NPT has been criticised for not explicitly addressing the effect of power on implementation work.(156) The original authors of NPT highlight that although power is not explicitly addressed it is implicit that actors must have agency to do the work to enact a practice.(168) Therefore factors which limit agency, or coerce or obligate individuals into collective action, such as organisational hierarchy and other architecture of power, may be identified by NPT as factors which inhibit work and therefore whether an intervention is adopted. Focusing on the work that all actors do both individually and collectively to create and maintain the space did highlight issues of power, the work required to overcome power, and where the burden of work lay. Patient PPG members had little agency to affect communal specification, communal appraisal, or the enrolment of staff. These were invited spaces and the patients were required to join in or leave. A disproportionate amount of the work of legitimation fell to PPG members, and this was rarely recognised, often rendering the space unsafe due to fear of prejudice. However, using NPT to focus on the work of creating space, also highlighted what Cornwall describes as the productive effect of power.(50) This was demonstrated in Practice 2: contractual obligations imposed on staff the necessity to create the participatory space, this created the space and the opportunity for patients to have influence. By focusing equal attention on all actors we were also able to identify the effects of power between staff members, due to organisational hierarchies, and between PPG members, due to social and structural norms.

NPT has previously been combined with Participatory Learning and Action (PLA) in order to address NPTs limited attention to power.(121, 154, 156) PLA is a specific participatory methodology which utilises participatory methods and facilitation to equalise voice during collaborative working.(121) De Brún et al suggest combining PLA and NPT may be useful when designing and enacting interventions by addressing power dynamics between stakeholders during the implementation process.(156) This approach was successful in helping stakeholders from diverse backgrounds collaborate to adapt and implement guidance on cross-cultural communication in general practice.(121, 154) This is the approach this project initially took, using NPT to identify potential facilitators and barriers at the intervention design stage, and choosing to use participatory methods to practically address power during the implementation (Chapter 3). However, our analysis goes further, utilising NPT to explore the space around the participatory methods. This identified power, in the form of agency to influence the shaping of the space more widely than equity of voice within meetings, that participatory methods have been previously shown to address.(121, 156). For example, who was invited to the meeting space and how they were invited. It also highlighted the effect of power on the work to maintain the space. In the absence of communal appraisal, patients lacked the agency to challenge controlling staff and maintain the new space.

Renedo and Marston have previously explored NHS public contributors negotiation of participatory space.(57) They observed that in the absence of agency to influence institutional spaces, public participants found work arounds to create radical alternative spaces where they could still achieve impact. Renedo and Marston focused solely on public participants' participation in the space and not staff, and the radical alternative spaces they describe were often only inhabited by public contributors and not staff. Our analysis suggests that to achieve partnership working and share decision making, both PPG members and staff need to contribute to the participatory space, and for some PPG members they only gained agency to do this during the intervention. However, we may be missing interconnected spaces which were providing opportunities for patient influence outside the PPG space. These could include the community spaces in which patients in both practices inhabit, and the wider organisational spaces within the NHS that some patients go on to influence. In linked work, Renedo and Marston discuss the negative impact of professionals' contradictory discourse on public contributors' identity.(271) Public contributors were forced to work to develop "*self-images"* which fit the professionals' discourse. This was often a negative process for public contributors which limited their participation. Our findings about the work of legitimation within the space, support their analysis. We also extend it by recognising the additional effect of other public contributors discourse and social norms on patient legitimation. This is supported by Kohn who found that inequalities in social status were reproduced, even in egalitarian deliberative spaces.(272) Other authors have focused on how public contributors construct and present legitimate roles.(102, 273) Cornwall describes this work as *"pragmatic opportunism"* and learning to *"play by the rules"* within a participatory space.(50) Our analysis shows legitimation work was linked to whether the work in the space was legitimate, as legitimate work helped demonstrate the PPG members were *"useful"* to the staff. But there was also a burden of internalised legitimation work overcoming structural discrimination within healthcare and wider society in order for PPG members, and some members of staff, to feel they have the right to occupy the space. This is the work that Freire describes as raising consciousness and is a prerequisite to overcoming oppression.(109) The intervention provided PPG members with a way of presenting legitimacy, the space is what supported some of them to become more conscious of the possibilities of their role.

7.3.3 Strengths and limitations

The framework is based on intensive work with two practices each over the period of a year. As discussed in Section 5.4, we used rigorous methods to collect and analyse the data. We triangulated observational notes (from different observers), documentary analysis, and semi-structured interviews.(189, 190) The CRG were involved in all aspects of the analysis providing participatory validity and reducing bias through the discussion of meaning from multiple perspectives to generate our coding frame and double coding.(108, 189, 190) We focused on the work of both patient PPG members and staff, and have combined this data which is rare in the literature. However the work is based on only two practices although they were considerably different. This is an advantage of using an established implementation theory such as NPT, enabling synthesis of findings with an existing knowledge base.(168, 274) We were able to identify similar component mechanisms of work in both practices, but this framework needs to be tested further to see if the same mechanisms would apply in other practices and other contexts.

There are many debates about the positioning of the qualitative researcher within observational research.(104) PAR argues it is impossible to control for the influence of the researchers on the knowledge they create, and it is more important for researchers to be explicit about their subjectivity and reflexive about how this influences their work.(114, 275) Therefore, we actively chose to conduct this analysis including the work of the CRG. Who the co-researchers are had an impact on the intervention and the resulting space. My status as a GP helped recruit practices and encourage staff to commit to the work. One co-researcher who is a British South Asian woman, helped facilitate meetings in Practice 1. This appeared to provide a visible expression of the space being safe (or safer) for people of colour. We also recognise that having pre-designed the intervention, we were effectively doing something *to* the space, rather than working *with* those within the space. Therefore it is essential that further research explores the impact of who the facilitator is and how they work *with* the actors in the space.

The follow up of Practice 2 ended early due to the Covid-19 pandemic. Covid-19 meant it was unsafe for face-to-face meetings to be held and the contractual requirement to work with PPGs was paused due to workload concerns.(276) We have evidence that the intervention changed relationships within Practice 2, but also concerns that the space was not going to be maintained following the first and only follow up meeting. It is possible that the space created in Practice 2 would change again into a new space where new PPG members were discouraged, and existing PPG members learned to play by the rules of the game reducing their authentic challenge. Or as Cornwall suggests *“Issues of power and difference may not only undermine the very possibility of equitable, consensual decision-making, they may also restrict the possibility of “thinking outside the box”, reinforcing hegemonic perspectives and status quo reinforcing solutions.”* p13.(50)

Finally, in both practices, but especially Practice 1, we only interviewed participants who were enthusiastic about the space. In Practice 1, one participant sent critical feedback by email, but would not engage in an interview. A number of participants did not return after the first intervention meeting, although one did say this was due to ill health. Without interviewing these individuals we cannot say whether the new space was excluding some voices.

7.3.4 Conclusion

Focusing on the work that actors invest in to create and maintain space enabled synthesis of the learning across two different organisational and PPG spaces. Utilising space as an analytical tool allowed us to focus on the work around the meetings as well as the work within meetings. This demonstrated that the action and the space are inseparable. The action must be credible and legitimate, and the space must be inclusive, equitable, and safe, for meaningful partnership working and shared organisational decision making to be achieved. Both the action and the space require the investment of effort by all actors. Recognition that all component mechanisms of the work of creating and maintaining the space are essential and interrelated, and that the work is continuous, but more or less visible at different times, allowed us to understand whether our intervention was successful. The analysis suggests we did create an inclusive, equitable, and safe space, in both practices, but also that this was not maintained as the work of communal appraisal was missing from our intervention. In future work we will aim to strengthen this component within the intervention, as well as exploring how to make the work of facilitation more visible and sustainable. We hope this would help maintain the participatory space after the intervention. The framework we have developed focuses on the component mechanisms of the work actors invest in to create and maintain participatory space, rather than a prescriptive toolkit or guideline. Therefore, it is potentially flexible enough to be used in other settings to design and evaluate participatory spaces.

8. Discussion

8.1 Summary

Patient participation groups (PPGs) are the primary mode of patient participation in the organisation of English general practice.(8, 25, 64, 73) They have been a mandatory requirement since 2015 (8), against a five-decade backdrop of differing participatory rationales.(1, 25, 38, 62, 64, 71, 72) This has resulted in role confusion, issues around representational legitimacy, and ongoing questions about power and patient influence. This project had two aims.

- To develop and test an intervention to strengthen the role of patient participation in general practice service improvement.
- To explore the space and relationship between patients and general practice staff when they try to work together to share organisational decision making.

The original outline of the intervention combined two mechanisms of participation: *partnership working* to share decisions about adapting a prioritisation survey, and planning and implementing action based on the survey results; and *consultation* with the wider population through the prioritisation survey. This approach was based on theoretical constructs operationalised by Boivin in an earlier successful participatory priority setting intervention, and consistent with recommendations to combine participatory methods (Chapter 1).(33, 36, 50, 101, 102) The original outline aimed to enable patients and staff to **share credible knowledge** about services and service improvement, address **representational legitimacy** through a prioritisation survey, and address **power** to equalise patient and staff voices in decision making.

Throughout the project I worked with a multi-stakeholder co-research group (CRG) as a participatory action research group (Chapter 2). We designed an adaptable prioritisation survey (Chapter 3 and 4). By reflecting on our experiences of working together, we were able to explore barriers to, and facilitators of, partnership working between patients and staff (Chapter 3). This process enabled us to develop a detailed but flexible intervention (Appendix 14) that reconceptualises PPGs as participatory action research groups, aiming to bring about change whilst exploring the process of change. The intervention included: a series of deliberative meetings recognising all stakeholders as having different credible knowledge to share, a prioritisation survey distributed by patient PPG members to increase statistical and democratic representation, and participatory methods and facilitation to structure meetings to enable equal voice. We also developed Boivin's theoretical constructs.(102) We identified that all stakeholders have credible knowledge, and patient knowledge extends beyond the experiential. We found that representational legitimacy is important for all stakeholders and is increased through multiple approaches to representation. PPG members reaching out to the wider patient population focuses on democratic legitimacy and the skills required to achieve this. Finally, we argue in Chapter 7 that power in participation is not just about equity of voice, but also about who has the power to invite, and who is invited to participate.(35, 50)

The intervention was field tested with two general practice PPGs. We utilised a systemic action research approach to field testing, integrating the local PPG level inquiry with systemic CRG level inquiry (Chapter 5). This demonstrated that the intervention did redistribute power and achieve instrumental change, enabling patients to influence service improvement priorities in both general practices (Chapter 6). Collective voice was strengthened by PPG members meeting without staff to explore different features of general practice. Both PPG members and staff changed their votes as a result of collective deliberation. This process of adapting the survey was feasible in both practices. PPG members were encouraged to ‘be representatives’ through considering features of general practice related to equity and social justice, and by talking to other patients whilst handing out the survey in the waiting room. Compared to other patient surveys, there was a good response rate and this was more demographically representative of the practice population when handed out by PPG members in the waiting room. This suggests that patients possess the skills needed to ‘be a representative of the wider patient population’ and this is a valuable role. In both practices, the surveys produced statistically significant results. The results stimulated action that would not otherwise have been considered by the practices, including rebranding as ‘the listening practice’ and associated increased focus on listening to patients, and improving privacy in the waiting room. These were patient centred rather than clinical actions. However, action plans were not always based on the results of the survey (e.g. ‘raising awareness of services’ and ‘alternative appointment systems’), raising ongoing concerns about representation. A surprising observation, because we had not specified this, and an outcome, was the participation of the whole practice team in at least one of the intervention meetings. This increased awareness of and interest in the PPG by staff who were not normally involved with the PPG.

The intervention field testing suggested that more work was done than participating in meetings and distributing a survey alone. Drawing on normalisation process theory (NPT) and Cornwall’s framing of participatory space, our evaluation suggested that this work entailed creating and maintaining a participatory space (Chapter 7).(50, 168) This involved completing the work of the task (adapting and distributing the survey, and developing an action plan), but also relationship building work related to creating an inclusive, equitable, and safe space. This involved all actors investing effort in: understanding the space, committing to the space, working in partnership within the space, and appraising the space. The space changed over time, and was influenced by, and influenced, other interconnecting spaces, including the practice space and wider social norms. The intervention changed the space partly due to facilitation by the CRG and the use of participatory methods. This resulted in increased confidence of all actors. However, maintaining the new space was inhibited by a lack of opportunities to reflect on this work, and a lack of agency of key PPG members and supporting staff lower in the organisational hierarchy. Thus, while feasible and impactful, this raises new questions about the resourcing and maintenance of inclusive, equitable, and safe participatory space in general practice. However, it also suggests that it is worthwhile pursuing participatory spaces as we observed unanticipated ripple effects on the practice space and wider practice team that could potentially lead to cultural transformation. These included increased reception staff interest in the PPG in Practice 2 resulting in them making suggestions for service improvements, and staff in Practice 1 attending a community event outside the practice.

8.2 Comparisons with the literature

This thesis started by drawing on frameworks of participation by Arnstein, Dean and Cornwall, to explain patient participation in English general practice and how this has influenced PPGs.(33, 36, 50) These same frameworks are useful in understanding the intervention and its impact. There are three key points: conceptualising space, the role of patients as decision makers, and impacts.

With regard to conceptualising space, Cornwall described four typologies of participatory spaces in which the public attempt to influence policy decision making.(50) PPGs most closely resemble ‘regularised relations’.(50) They are institutional, invited, regular spaces. The majority of patients involved in this thesis, and in the literature, joined their PPG as they were invited by a member of staff.(71, 75) PPGs are initiated by staff, either in response to personal motivation, or more commonly, in response to financial incentives and contractual requirements. Interviews with GPs in 1980, found GPs motivated to set up PPGs based on values were positive about PPGs, whereas GPs without PPGs were more sceptical.(62) Little appears to have changed: in Practice 2 the PPG was initiated in response to contractual obligations, and the senior GPs were still sceptical about their purpose and legitimacy. Brown observed that general practice approaches to patient participation were shaped by organisational values, and patients were aware of this.(67) Cornwall supports this and emphasises that the structure and relationships within invited spaces are shaped by the inviting institutions.(50) This was certainly the case in Practice 1, where staff controlled the structure, function, and content of the pre and post intervention space. In Practice 2, the responsibility for the pre-intervention space had been delegated to the patient PPG members, but without redistribution of power to influence the participation of staff, which remained under the control of the practice. This is an example of what Cornwall describes as those in power ignoring the space and hence limiting its' transformative potential.(35)

Arnstein's ladder of participation helps to explain the heterogeneous relationships between PPG members and staff in invited PPG spaces prior to our intervention.(36) In Practice 1, staff approached the space as an opportunity to share information and consult the patient population on changes. In Practice 2, staff used the space to placate patients and achieve their contractual obligations. In our intervention development focus groups we observed a variation on these themes. According to Arnstein, none of these relationships is likely to result in redistribution of power, which she describes as crucial for meaningful participation.(36) The intervention we designed explicitly aimed for PPG members and staff to work in partnership, sharing decisions and hence redistributing power, in pursuit of the common good of patient centred services for all patients. We did not aim for the top rung of Arnstein's ladder, citizen control, recognising that GPs and other general practice staff have professional knowledge and organisational experience also essential for service improvement decision making.

Working in partnership to share different knowledge fits within Dean's mode of participation of 'knowledge transfer'.(33) Dean describes this mode of participation as a space in which different experts, with different knowledge, meet to exchange their knowledge creating a multidimensional understanding of a problem and potential solutions for the common good. Within this space patients are framed as 'experts by experience' and their experiential expertise is, in theory, valued as equal to professional expertise. Similar to PPGs, and Cornwall's invited spaces, the rules of participation in this mode are prescribed by the institution.(33, 50) However, there are two differences between this mode of participation and our intervention. Firstly, our intervention frames all participants as having multiple forms of knowledge, not just professional or experiential expertise. Secondly, Dean's mode of 'knowledge transfer' is described as experts sharing information so that a third party policy maker, who is an expert in decision making, can make a final decision.(33) Our intervention, attempts to subvert who the policy makers are in general practice. Patients are framed as expert decision makers: through the prioritisation survey asking them to make difficult choices between alternatives, and the intervention meetings. All the intervention meetings had an element of PPG members taking responsibility for decisions, firstly about what goes into the survey, and then about the action as a result of the survey. This effectively moves our intervention towards Dean's mode of participation 'collective decision making'.(33)

Dean describes the 'collective decision making' mode of participation as a space where the public, and all stakeholders, have equal power in all decisions.(33) He describes five principles of this mode of participation: direct participation of all, equal power, decision making at the lowest appropriate level, participation is part of everyday life, and participation as educational. Our intervention meets some, but not all of these principles. Multiple meetings allowed all staff to be involved in decision making, and the prioritisation survey provided an opportunity for all patients to be involved (however, there remain concerns that this was coercive rather than allowing direct participation). Everyone in the voting meetings and action planning meetings had equal power in decision making. We attempted to make the prioritisation survey accessible to all patients including those with low literacy, despite it involving complex decisions. Creating deliberative space in meetings aimed to be educational: informing PPG members about services and resource constraints, and staff about the reality of patient experience. We had hoped the intervention would result in a situation where patient participation in decision making was a routine part of everyday practice life. However, this did not happen for two reasons. Firstly, the intervention did not provide reflective space for patients and staff to discuss what had changed, whether new ways of working should be maintained, and how. Secondly, as the CRG created the intervention space, there were limited opportunities for PPG members or staff to negotiate and make decisions about the conditions of participation within it. In this sense the intervention effectively did something *to*, and not *with* the PPGs. The CRG became the inviting party, inviting both PPG members and staff to meetings and prescribing the content and format of meetings. This suggests our intervention was what Cornwall describes as a 'fleeting formation' participatory space, within the regular PPG space.(50) The intervention space was invited, predetermined, and bounded. This is similar to other academic attempts to increase participation such as experience based co-design, where similar concerns about sustainable change have been raised.(129, 131, 132) Overall this suggests our intervention sits between Dean's 'knowledge transfer' and 'collective decision making' modes. Dean conceived his quadrants as permeable, and recommended using them to map participation when planning or evaluating participatory spaces.(33, 56)

With regard to patients as decision makers, a notable observation throughout the thesis was that both patients and staff appeared, but rarely vocalised, that they were uncomfortable with the role of patients as decision makers. Patients did not like being forced to make difficult decisions in the prioritisation survey. PPG members also found the card sort challenging, in both the intervention development focus groups, and in the field testing PPGs and practices. In the focus groups, patients did not want to make decisions without staff being present. In the intervention card sort meetings, patients struggled to exclude any of the features, often questioning their own legitimacy to decide. Haesebaert et al observed similar patient concerns in their participatory action research project to establish patient engagement councils in Canadian general practices.(100) Prior to the voting meetings, staff in both field testing practices, expressed reservations, worrying PPG members would vote for features outside their control to change, resulting in Practice 2 taking steps to 'out-vote' the PPG members. Evidence suggests that patients' wishes about their level of participation are heterogeneous, and many patients do not want to be responsible for organisational decision making.(71, 75-77) Dean also found that both the public and policy makers have heterogeneous views about their preferred mode of participation.(56) Policy makers were much more comfortable with a 'knowledge transfer' mode where they retain control over decision making.(56) Arnstein offers an alternative explanation of this discomfort with the concept of patients as decision makers: that both the powerful and disempowered erect barriers to the redistribution of power.(36)

Arnstien identifies several barriers to the disempowered participating meaningfully, and claiming power.(36) These include lack of socioeconomic infrastructure, knowledge, and organised collective accountability. Prior to the intervention, there was evidence of these barriers in both practices. In Practice 1, there was no collective voice, and some PPG members felt their role was futile and felt alienated by other PPG members. In Practice 2, PPG members had lost trust in the practice staff partly due to a lack of knowledge sharing. Our intervention changed this. In Practice 1, we focused on establishing relationships between PPG members and creating collective voice by making meetings fun, introducing warm up exercises, having a patient only card sort meeting, and providing training and encouragement to talk to other patients and 'be a representative'. In Practice 2, we focused on highlighting different forms of knowledge and skills, and sharing this knowledge between PPG members and staff to re-establish trust. Arnstein also identified barriers that the powerful enact to maintain power including racism, paternalism, and resistance to redistribution of power.(36) We also observed similar traits throughout the project. In the CRG, focus groups, and intervention PPGs, there were examples of staff showing resistance to the redistribution of power. The most significant example was the CRG recognising we would need to allow GP partners the final say on the features in the survey, before they would enrol in the intervention. Paternalism was demonstrated by practice staff not recognising the knowledge and skills of PPG members, and giving PPG members favourable treatment without them knowing. Finally, there were examples of exclusionary behaviour between patient PPG members, including racism. These behaviours were not challenged by staff. This may reflect a lack of training or experience in challenging this behaviour, or it may represent conscious or unconscious bias. There is increasing evidence of institutional racism in the NHS (277, 278), a culture of not listening to patients in general (14), and patient leaders describe the NHS recreating exclusive and unwelcoming participatory spaces.(279) Cornwall argues that participatory spaces are influenced by other spaces.(50) Our data demonstrates this: in Practice 1 the pre-intervention space reminded some PPG members of other institutional spaces in which they had felt excluded and alienated due to structural racism. This is an example of the wider social-cultural influences on PPGs. It is also a strong argument for the need to create new participatory spaces, which are sensitive to the experience and background of all stakeholders.

Finally, with regard to impacts, the intervention did disrupt some barriers to redistribution of power, and where this happened self-confidence increased and relationships between PPG members, and between PPG members and staff developed. As confidence and relationships developed, commitment to the task developed, and when the task was successful, commitment to working together and co-ownership of the space developed. Focusing on the work of creating and maintaining participatory space highlighted this process and begins to address the gap in the literature Cornwall described regarding the micro politics that shape the space.(50) Cornwall also identifies outstanding questions about the architecture of participatory space. Our intervention suggests the architectural structure of the space is formed by the task the actors undertake, providing scaffolding for the tacit relationship work to occur. This task must be credible and legitimate and therefore is likely to be instrumental enabling actors to appraise their work and build confidence.

In the intervention, and many other participatory projects, legitimacy is related to representation: specifically who is involved and who decides. Patients recognise, and our results provide empirical evidence, that who is in the decision making meeting effects what decisions are made.(251) In our intervention representational legitimacy was achieved by bringing patients and staff, including the wider practice team and patient population, together around a credible task. PPG members were encouraged to think about other patients and social justice when prioritising features, and distributing the survey. The survey results were used as a starting point for discussion rather than an outcome. This involved combining participatory approaches, *partnership working* and *consultation*, which is recommended by Arnstein, Dean and Cornwall, and has worked in other interventions.(33, 36, 50, 101, 102) However, there were still many patients missing, particularly younger patients and patients from ethnic minorities, and personal agendas appeared in both action plans. Dean suggests a potential solution is a '*complex participatory system*' with different modes of participation, all interacting, and offering different opportunities to participate for a wide public with heterogeneous preferences for participation.(28, 33) This was attempted within the NHS through the ambitious NHS Citizen project.(28) This involved: a deliberative system involving civil society actors setting agenda's for mini-public deliberations, training and a culture change programme for commissioners, and a participatory approach to the design. There were some successes, but more failures. These related to: the powerful resisting redistribution of power, creating a backlash to public challenge; representational illegitimacy as the public were widely distributed rendering the collective voice unseen; and issues about boundaries and purpose in a large organisation.(28) However, our intervention suggests a local smaller scale complex participatory system may overcome some of the challenges of single mode participation. Our framework demonstrates this needs to be done sensitively recognising the need to create safe and inclusive participatory spaces, and that this requires skill and effort which are not currently in abundance in general practice organisations.

The creation of a participatory system of interconnected institutional invited spaces may increase opportunities for patient participation and reach a wider public. However, Cornwall warns that this must not be at the expense of spaces outside institutions such as support groups, protest, activism, and complaint.(35, 50) These are self-created spaces where the public set the agenda and the terms of participation. There is evidence that practice staff do use PPGs to ameliorate complaints and therefore this is a real danger.(64, 71) There is a potential that this is what our intervention did in Practice 2. Pre-intervention the PPG was self-organised and campaigned for the practice to change. The intervention changed the space and the PPG members and staff started working in partnership, but there were indications that the group was now closed to new patients and future challenge would be resisted. The opposing argument is that the pre-intervention challenge presented by Practice 2 was rarely successful. The personal experience of the co-researchers is that challenge can lead to catastrophic PPG relationship breakdown with patients having to move general practice. Therefore while these dangers need to be recognised, our results suggest *partnership working* within an invited institutional space is of instrumental worth, especially compared to no participatory space.

A final argument is that instrumental participatory spaces can result in transformational change.(35) Recent research suggests that *partnership working* between patients and clinicians challenges clinicians' professional identity.(280) Clinicians balance two opposing identities when working with patient partners on service improvement: that of caring paternalistic clinician, and that of an equal partner. Partnership working challenges professional identity, either resulting in a discourse of patient partners as illegitimate, or potentially transforming paternalistic approaches within the clinical consultation. This was demonstrated in our project. There were times when I held back from challenging some CRG members as I would a colleague, because unconsciously I was framing them as vulnerable patients. In Practice 1, the staff were sceptical about the purpose of attending a community event (one of their action plans), but they reported back it was refreshing talking to patients outside the practice, and they would do this again. In Practice 2, the reception staff attending meetings resulted in human relationships developing with the PPG members. In all cases this resulted in reappraisal of the participatory space. Therefore transformative change can happen in instrumental institutional spaces, even if they are not challenging. The key factor appears to be staff interacting with patients as people. This may disrupt their identity which may have wider unanticipated effects on other spaces beyond the service improvement. Traditional discourse about participation has focused on its potential to empower and transform communities.(50) This project adds that institutional participatory spaces may have the potential to transform institutions.

8.3 Strengths and limitations

8.3.1 Participatory action research approach

The strength of the participatory research approach is that it has been found to have both instrumental and transformative outcomes, as a result of pursuing action and learning.(24, 134) Working with the CRG as a participatory action research group has had positive outcomes in terms of the intervention, the research process, and the co-researchers (Table 8.1).

Table 8.1. Known outcomes of participatory research and their relevance to this project (24, 134)

Outcomes	**Relevance to this project**
Culturally and logistically appropriate research	The intervention is logistically appropriate as it was specifically designed to fit with the existing working arrangements of practices and PPGs. Co-researchers facilitating meetings highlighted attending to culturally inclusive practices, such as welcoming behaviour and refreshments.
Increased recruitment	The focus groups and field testing PPGs and practices were recruited utilising the network of contacts within the CRG. When we tried to recruit outside of this network, we met more mistrust. One co-researcher had an established relationship with the local Healthwatch who recruited pilot survey respondents on our behalf. Patients distributing the survey in the waiting room increased the response rate and diversity of the sample.
Capacity development for all stakeholders	One co-researcher fed his learning into his own PPG. One PPG member joined the University of Leeds Patient and Carer Community which supports medical student teaching. All co-researchers have developed their research skills, many of the GPs used the project in their annual appraisals. Some co-researchers have included this work in job applications and curriculum vitae. One co-researcher who does public speaking has drawn on this experience in his talks.

Productive conflicts	Conflicts within the CRG provided evidence of barriers to the redistribution of power between GPs and patients allowing us to problem solve potential solutions for the intervention. See Chapter 3 for examples. Conflicts also improved the research process. The co-researchers struggled with the deductive NPT analysis resulting in conflict. As a result we changed to an inductive analysis process followed by mapping emerging themes against NPT constructs. NPT can be used deductively and inductively, other researchers have found the inductive approach more satisfactory.(170, 245) This change shifted our focus to the work of creating and maintaining participatory space.
Increased quality of outputs and outcomes over time	The intervention continued to evolve over the whole project, not just during the interventional development phase. For example, the co-researchers who helped facilitate intervention meetings had a different style from mine, which was similar to the efficient practice manager style. This highlighted the need for meetings to be fun and welcoming, strengthening the intervention and its success, especially in Practice 1.
Sustainability of interventions	The co-researchers are committed to ongoing work as a co-research group, despite the fact we currently have no ongoing funding. They have said this is because they enjoyed the process, are interested in the topic, and have developed trust relationships. During the Covid-19 pandemic, I worked full time clinically whilst the CRG conducted follow up interviews with the patients in Practice 2, keeping the project progressing.
System transformation and spin off projects	The project has already had two spin off projects: (1) The CRG developed a film about our experiences of working together for the University of Limerick, Ireland, PPI Summer School. This film has been shared with other co-research groups and has been used in three post-graduate research courses. (2) We successfully applied for further funding to develop a theatre workshop to support PPG members and staff to reflect on their PPGs in a safe space. We have piloted this in the local clinical commissioning group of the GP co-researcher, and are talking to contacts in NHS England to think about scaling up this work and the intervention. Direct system transformation as a result of the action plan in Practice 1. Indirect system transformation in both practices in their approach to patient participation: Practice 1 staff attending a community event outside the practice, Practice 2 reception staff developing relationships with the PPG members to pursue common interests. See also Section 8.1 and 8.2.

The defining principle of the PAR paradigm is participation throughout the research process.(108) However, Salsberg et al stress that participation should not be at the detriment to scientific quality and rigour.(19) They argue that in order for the outcome of the research to be useful to those participating it must be rigorously conducted research. Therefore, there may be aspects of a study where the academic researcher conducts the research on their own. This was the case in this project for the statistical design and analysis of the DCE. Both aspects are established scientific processes and the CRG were happy for me to undertake these alone. In addition, this thesis is my own writing based on our collective work. Salsberg et al suggest the key minimum requirement is co-researchers participating in developing the research question, interpreting the results, and agreeing dissemination messages. The CRG participated in all three key activities, and additional activities of data collection and analysis. This additional participation led me to reflect on the balance between participatory validity and scientific quality:

- During intervention development I prioritised collecting primary data, and data quality, over the participation of the CRG in the data collection. In hindsight, this represents my lack of trust in the co-researchers at the start of the project. When the CRG were involved, we collected unanticipated and useful data, suggesting an alignment of participatory validity and scientific quality.
- I had some concerns about the quality of co-researcher interviews during the evaluation. However, the CRG were keen, we had developed a trusting relationship, and this was an opportunity to collect peer led interviews which might be rich in other ways.(243) The resulting interviews were different to the ones I would have conducted. One co-researcher explored structural racism that I would have missed. However, co-researchers missed opportunities to probe with follow up questions. More training, better topic guides, or doing the interviews in pairs may have avoided this, but these solutions also have potential trade-offs regarding the interview quality.(243)
- We designed the prioritisation survey to be short so more people would participate. This was at the expense of validity and reliability measures which extend survey length. Consequently, the survey is not as rigorous as it could have been. However, the survey is more rigorous than many PPG designed surveys and did stimulate change.

8.3.2 The co-research group

The strengths and limitations of the CRG are related to the participatory space that we created throughout the project (Table 8.2). The space is similar to a PPG space in that it is an institutional invited regular space. The institution is the university, I did the inviting, and the content of our work was limited by the fellowship funding and constraints of the PhD.

Table 8.2. The work of creating and maintaining the CRG space based on NPT (168)

Work needed	Strengths of the space	Limitations of the space
Understanding the space	The concept of strengthening patient participation resonated with everyone. Understanding of the space developed over time, especially after developing a partnership agreement. Taking on roles within the space deepened understanding of how we wanted to work together.	The space was defined by the fellowship. Initially I felt some co-researchers understood their participation as supporting my PhD and holding me to account, rather than working on something in partnership. The space was influenced by other external spaces including my supervision team, and other PPI groups that the co-researchers were part of.
Committing to the space	My status as a GP helped when recruiting co-researchers especially GPs. The CRG was representative of the patients who get involved with PPGs. We regularly discussed representation and were reflexive about who we did not represent. Seven patients and one GP remain committed to the group.	We were unable to recruit practice managers and other staff who support PPGs. Meeting timing and location, and their agency over their work affected their ability to participate. The CRG was not representative of the wider patient population. Twelve people withdrew from the CRG in the early stages. Their reasons included other workload considerations, the slow pace of research, or unmet expectations.
Working in partnership within the space	There was a clear link between the credibility and legitimacy of project tasks and the work of creating and maintaining space. The more co-researchers participated, the more they committed to sharing responsibility for the project and the space. This was demonstrated in their language changing from “you” to “we”. Increasing the frequency of meetings and work between meetings, increased our time within the space and our collective understanding of the space and partnership working.	When the co-researchers were not confident or did not think the work was credible or legitimate, they struggled. For example, confidence fell in our first attempts at qualitative analysis, resulting in some co-researchers holding me to account rather than working in partnership. There was an imbalance in the amount of time we had for the project. I was working on it 60% of my time, co-researchers were initially coming to meetings every three months.
Appraising the space	When we made time for reflection and communal appraisal, our collective understanding increased, and trust developed.	We did not make enough space for reflection. The co-researchers had high expectations of the project and are still frustrated by the slow progress of research.

8.3.3 Framing patient participation as a complex intervention

Increasingly, authors are arguing that patient participation should not be defined as an intervention with a measurable outcome.(116) There are two arguments for this, a technical and a moral perspective. Technical arguments concern the ability and appropriateness of attempting to measure any complex intervention, such as patient participation, in a complex adaptive system.(105, 106, 116) Moral arguments frame patient participation as a right, therefore instrumental measurement of its impact is immaterial.(116) However, the CRG argued that patients participate because they want to see change happen. We tried to navigate this field by defining our complex intervention as attempting to interrupt systemic patterns.(143) This was appropriate as the mandatory requirements for general practices to have PPGs, appears to routinize potentially tokenistic practices, creating disempowering systemic patterns.(70, 71) However, due to my background, the funding context, and the university and PhD institutional requirements, we also attempted to delineate and produce a describable 'intervention'. This may have resulted in a specific focus on the intervention components, with less attention to their interactions.(18, 196) This balance between a flexible yet potentially definable and replicable complex intervention has been both a strength and a limitation throughout the work.

The limitations of this approach have been living with the uncertainty of what the complex intervention was. At times the CRG, my supervisors, the field testing PPGs and practices, and I, have all struggled to define the intervention. The biggest misconception has been that the intervention is the prioritisation survey. This was evident in the field testing interviews where interviewees used 'the intervention' and 'the survey' interchangeable. This was especially so for the Practice Manager in Practice 1 who defined the success of the intervention as acting on the action plan resulting from the survey. Attempting to define the complex intervention and have a package ready for field testing resulted in the CRG *doing something to* the field testing PPGs and practices, even though we were attempting to work *with* them. The field testing practice PPG members and staff were not involved in designing the intervention and therefore had to take a leap of faith and trust our process (which they did). We did not provide enough opportunities for them to reflect on why the space changed, and what they could do to maintain the space. The survey was seen as a technical instrument and participants focused on this as the intervention, rather than the whole package of work. For me, the uncertainty about what the intervention was only resolved during the analysis of the interviews when we reconceptualised the intervention as creating and maintaining participatory space. One co-researcher in a meeting to review our analysis described the intervention as 'bespoke therapy', emphasising the relational work of the intervention and the multiple opportunities to address systemic patterns. We had used the opportunity of the intervention to work with the practices, assess what their issues were, and address these. Therefore we spent a lot of time building relationships between PPG members in Practice 1 and unpicking conflict between PPG members and staff in practice 2. Whether this ‘therapy’, or relational work, was the intervention that changed the space, rather than the more concrete and describable structure of the meetings and survey is open to interpretation. However, our analysis suggests without a definable task (adapting, conducting, and acting on the prioritisation survey) to offer practices, and to bring PPG members and staff together in the same space, we would not have been able to do this ‘therapy’. Therefore the intervention is not only the structural and describable intervention components, but also how they interact with each other and the people and relationships that enact them. This does leave a challenge going forward of describing the intervention and knowing what to offer.

The work of extending NPT to explore context and complexity provides useful language for discussing the balance between flexible and describable intervention implementation.(169) May describes complex interventions as having similar properties to plastic: successful interventions are able to mould to the context. He also describes context as elastic: it must be able to change shape to allow an intervention space. May thus describes implementation as the collective action of participants to adapt the intervention to the context and to adapt the context to allow the intervention space to work.(169) Our intervention was plastic and able to adapt to two very different practice contexts, and both practices were elastic, accommodating in providing space (meetings and staff) for the intervention to work. However, this relied on considerable effort from the CRG in the form of facilitation, and changes to the context in Practice 1 did not appear to last. This raises concerns about sustainability and scalability of a flexible intervention which relies on facilitation.

8.3.4 Quality of the intervention development and field testing methods

The majority of the intervention development and field testing relied on qualitative data collection and analysis. Primary data was generated through our discussions as a CRG and from external sources including focus groups, ‘think aloud’ interviews, field testing observations, meeting documents, and in depth interviews with those participating in the field testing. This data was then discussed with, and analysed by the CRG enabling deeper reflection from multiple perspectives. This was a rigorous process which involved constant comparison within and between data sources with sense checking by different stakeholders within the CRG and my supervisors, resulting in rich description which developed and deepened throughout the project as described in this thesis. The intervention development data was discussed in a number of CRG meetings, this resulted in a coding framework which I applied to the data, and then shared with the CRG to sense check. Two of my supervisors reviewed a sample of this coding to ensure rigour to the coding framework. The results were then shared back with the CRG for further discussion. We followed a similar process for the field testing evaluation data, with an added step that each transcript was also coded by a member of the CRG. Double coding is seen by some as a mechanism to reduce bias in qualitative data analysis.(189) However, it is not the only mechanism, and other authors have employed similar co-analysis processes which are transparent and rigorous because of the number of perspectives involved and the constant and iterative discussion and checking of understanding.(281)

A large number of people participated over the whole project, across two different cities, however, for each element of data collection it could be argued that the sample size was relatively small. Sample size in qualitative research is a contentious subject.(274) The concept of saturation is often (mis)used to justify sample size in qualitative research. Saturation is actually a specific component of Grounded Theory analysis and explains the point at which no new observations are seen in the data. When sampling focus groups, ‘think aloud’ interviews, and field testing practices we took a maximum variation approach. However, this actually highlighted the vast variation in individual participatory preferences, general practice organisation, and PPG structure and function. Therefore, we cannot claim saturation was achieved, but it also was not what we were aiming for. This was especially the case for the field testing interviews where we interviewed everyone who expressed an interest, but this was only 14 interviews. Malterud et al describe an alternative approach to sample size guided by “information power” that demonstrates internal validity of new knowledge emerging from qualitative data.(274) Information power focuses on the amount of information held within the total sample, rather than the number in the sample. The information power of a sample depends on the aim of the study, the specificity of the sample, the use of established theory, the quality of the interview or data, and the analysis strategy. Therefore our sample size of 14 interviewers with PPG members and staff during field testing can be said to provide internal validity because:

- The aim of the field testing was to generate in depth understanding of the collective action of the intervention,
- This was a very specific sample limited to those who had experienced the intervention,
- We used the establish theory, NPT, allowing us to synthesis our findings with existing knowledge,
- I am an experienced qualitative interviewer and generated detailed interview transcripts rich in detail. The co-researchers had varying levels of prior interview

experience and hence the quality of their interviews varied. This difference in quality demonstrates the importance of interview quality to information power.

- Our analysis strategy involved integrating observations and field notes to explain what happened during the collective action of implementing the intervention.

Traditional co-operative inquiry would encourage the focus of inquiry to remain in the individual group.(113, 147) Whilst this can produce rich learning, it has been criticised for not producing transferable knowledge.(143, 157) This thesis is based on an intervention development process with one multidisciplinary team, and two volunteer field testing PPGs and practices who were considerably different. Therefore, the external validity and generalisability of our findings may be questioned. However, our use of an established mid-level theory, NPT (168), in both the intensive development and field testing of the intervention, and our systemic action research approach (143), emphasise the integration of different knowledge and the identification of transferable concepts, principles, and intervention components. This approach is how we identified the work of creating and maintaining participatory space, and developed a framework to describe this work which may be transferable to other settings. It is possible this learning might have increased, particularly around the impact of the doctor-patient clinical relationship, if we had utilised the practices of the co-researchers for the intervention field testing. We did not do this due to ethical concerns regarding disrupting the co-researchers’ individual clinical relationships. There is very little empirical evidence regarding the impact of the participatory space and partnership working on clinical patient-doctor relationships.(2) Therefore our ethical decision was influenced by our personal views. We made this decision as a group and I discussed it with my supervisors. However, I wonder how much influence I had on this group decision. Specifically whether my GP identity, and clinical paternalism, influenced the CRG to prioritise maintaining this clinical relationship above the potentially transformative learning opportunity that Codsi et al suggest partnership working may provide.(280) Further research is needed to explore this issue. This thesis adds that any further work would need to be sensitive, transparent, and conducted by a team of researchers with an established relationship of trust.

8.3.5 Discrete choice experiment

There were strengths and limitations of using the DCE method. GPs were attracted to the approach as they perceived forcing patients to make difficult choices would create empathy for them having to make similar decisions. This is consistent with GPs identities as caring professionals having to make tough decisions due to limited resources.(280) This was instrumental in recruiting field testing practices. The DCE also provided a consultation method different from the usual patient experience measures which have significant barriers to use.(86, 89) The added advantage of the DCE is that it potentially has more democratic validity as patients directly give their opinion, rather than experience data which is analysed and then a decision maker decides the priorities for action. Therefore the DCE was more consistent with a PAR approach. Patients did complete the survey and statistically significant results were produced in both practices. The DCE also provided a focused task for the PPG members and staff to come together to work on. Ultimately the DCE was designed and conducted by patients, for patients, achieving our aim of reframing who the policy makers are.

However, there are also multiple limitations of the DCE. It was complicated to produce and analyse, and given the lack of validity and reliability measures as discussed above, it may not be a scalable option.(235) The DCE had a high cognitive burden and despite our best efforts, the results suggest those with lower literacy did not complete the survey. Patients and co-researchers expressed concerns about forcing people to make difficult choices, equating this with coercion, and many respondents negatively perceived the survey, although as discussed in Section 6.6.4 this may demonstrate engagement with the decision making task. Co-researchers were partially accepting of the survey due to the fact that patients were involved in designing it and agreeing actions based on the results. However, it is possible that the wider patient population did not know or understand the PPG involvement, which has been a problem with previous attempts to combine participatory approaches.(28) Equally, negative reactions might be due to not wanting the responsibility for decision making for a population, which is not explored in the individual shared decision making literature.(77) We added a large free text box to the survey to allow patients to highlight other issues they were concerned needed improving. In Practice 2 this raised issues that the PPG were not aware of. This suggests PPG members, like GPs, are not ideal at representing the views of patients.(101, 118, 119)

The overall findings from this project suggest that the validity and reliability of the outcome of the DCE were much less important than the process of adapting, distributing and acting on the results. We frequently observed evidence of PPG members and staff not really understanding the survey, but agreeing to try it. The action plans tended to be only loosely based on the survey: they included actions about all the features in the survey, not just the respondents' top priority, and personal agendas influenced the final action plans. This is not necessarily a limitation as Burns describes it is more important that an intervention results in a change, than the process through which the change happened.(143) As discussed in Chapter 6 this has been observed in other research exploring the use of patient experience data, and has been linked to the legitimacy of the data and the context.(27, 89, 256) However, another explanation is that organisational decision making processes are similar to clinical decisions making processes which are based on “mindlines” rather than evidence.(282) Mindlines are a form of tacit knowledge which is socially constructed and influenced by the environment and relationships. Mindlines describe how decisions are made based on the time, place, people, and context in which the decision making occurs. This suggests that the whole intervention package is more than the sum of the DCE and the meetings, and the space in which decisions are made, and the opportunity for deliberation and sharing perspectives is crucial. Patients and staff trusted the results, despite not fully understanding them, because we had developed a relationship and participatory decision making space over the course of the intervention.

8.4 Implications for future research and practice

There are two broad areas for future development: developing and testing the complex intervention further, and developing the framework of the work of creating and maintaining participatory space.

As discussed, the intervention did have an effect in both field testing practices. However, due to Covid-19, we were unable to follow up with Practice 2. Equally we have already identified the need to strengthen opportunities for reflection within the intervention. The lack of reflection was partly due to time, and possibly due to all stakeholders needing a safe space before meaningful reflections can be shared. We are currently exploring Forum Theatre techniques with PPGs to see if this opens up opportunities for reflection within a safe space.(283) These could then be adapted into the intervention before further testing including a longer follow up period.

There are three other aspects of the intervention that we would like to explore further to see how significant these were. These are alternatives to the DCE as a method of consultation, the role of the facilitator, and the scale of the participation.

There were several concerns regarding the DCE as a method of consultation including: that it was coercive, that it excluded people with low literacy levels, that many patients did not like it, and whether it can be scaled up and utilised without a researcher being involved to provide the experimental design and analysis. This last point is something that would require more research. The initial fellowship proposal discussed potential follow up work involving turning the DCE into a digital tool with inbuilt experimental designs based on the number of attributes and levels, and a standard analysis package that could process the data remotely. This looks unlikely given concerns about attributes interacting, the ordering of attributes, and the complexity of the analysis. However, it is potentially one area to explore further with the company that produced the electronic version of the survey. The other possibility is to investigate and test alternatives to the DCE as the consultation mode of participation, especially alternatives which may be more inclusive of people with lower literacy levels. Alternatives include:

- Free text open ended questions “what would you like to improve at this practice?” asked in a survey or interview conducted by the PPG. This would add greater emphasis to the PPG ‘being representatives’ and a discussion with patients in the waiting room. This would allow patients the freedom to bring up any issue, as happened in Practice 2 where ‘improving privacy in the reception area’ was raised repeatedly in the free text comment box. However, analysis would be intensive and add an extra level of abstracted interpretation. This method would require sensitive framing to ensure the inclusion of components of individual shared decision making including choice awareness, information sharing, and values elicitation.(260-263)
- Best-worst scaling. This is another form of conjoint analysis, based on the same economic theory, however, it is less cognitively burdensome.(266) It may be an alternative to the DCE as it still forces patients to make a choice, but the choice is less challenging and potentially more inclusive of those with low literacy.
- Participatory ranking and rating tools. There are many different versions of these tools which aim to help groups prioritise.(150, 151) Some of these might be suitable to a waiting room or online exercise, and have been used in populations with very low literacy levels. These methods do not always have a statistical component, but this is arguably not needed if the process is transparent. The findings from this project would suggest that the outcome or top priority is enough to stimulate change rather than an elaborate statistical process.

Further research would be needed to test these different methods of consultation to explore whether they have an impact, whether it is the same or different to a DCE, and what the core components of organisational shared decision making are. The more basic methods described above may be more easily understood by PPG members allowing them to gain confidence and ownership over the process. However, professionals may judge them as less scientifically robust, effecting their willingness to enrol in the intervention.

The facilitator role was essential in both field testing PPGs and practices, however, even within the CRG there were different styles of facilitation, and the results could have been very different with another facilitator. It would be valuable to explore whether PPGs could facilitate the intervention themselves, without a facilitator. Our results suggest this would result in focus on the survey task rather than creating and maintaining the space, staff would be unlikely to participate, and there would be little reflection. It would also be valuable to explore the effect of different facilitators, with different styles and status. My status as a GP engaged staff and gained their trust, encouraging them to participate. Co-researchers encouraged informality and a relaxed environment. Both approaches to facilitation supported the intervention. Therefore I would be interested in exploring different facilitators and facilitator styles in future work. A Canadian action research project used expert patient facilitators, but they also had a paid researcher working with them.(100) The facilitator needs to be skilled and familiar with participatory methods, to support the work of creating and maintaining participatory space. This would be a new resource within general practice. Our results also suggest the facilitation would need to be ongoing and find a balance between being outside and inside the PPG and practice organisation. As new resources might be required, this would have implications in terms of scalability and sustainability.

One option to fund a facilitator, and to give them some critical distance from the general practice, would be to employ a facilitator at the Primary Care Network (PCNs) level. PCNs are groups of general practices in roughly similar geographical areas, that cover a population of approximately 30,000 to 50,000 patients.(284, 285) PCNs are seen as one way of providing community services and have been used to resource social prescribing. There has been a great deal of discussion about patient participation in PCNs, with some PCNs even considering inviting local councillors onto their boards, to provide elected democratic legitimacy. There have also been discussions about the relationship between PPGs and PCNs, with many patients, including co-researchers wanting a seat at the PCN table. However, there is less overt discussion about the philosophical rational for patient participation in PCNs, or what type of participatory space this would be. The CRG would like to investigate whether our intervention might be more suitable at the PCN level, where there are potentially bigger decisions about resource allocation to be influenced. However, if PPGs move to the PCN level, this may create a patient participation void in individual general practices. Further research and practice could explore linking PPGs and PCNs in a wider complex participatory system. Specifically how knowledge may flow (or not) between these spaces for participation, and how these spaces would interact.(50, 57)

Another area to explore would be mapping organisational decision making in general practice to understand the opportunities for patient influence. Part of the success of our intervention was having the staff card sort meeting within a practice meeting. This inadvertently encouraged other members of staff interest in the PPGs. The CRG would be interested in exploring how and where decision making happens within general practice, who the key decision makers are, and where the opportunities for patient influence lie. By identifying where decision making happens we could target these areas to develop opportunities for patients to participate in decision making, promoting participation in everyday decision making rather than a separate activity. This might result in a better understanding of whether the opportunities are in general practice or at the PCN level, and who the real decision makers are, which might help to establish whether a token GP in PPG meetings is essential or not.

Throughout this project the CRG have at times wanted to ‘prove’ whether the intervention works. When questioned on this they appear to mean through a randomised controlled trial (RCT). As PAR is flexible about methodology, there are participatory trials.(24, 111) Ultimately, a definitive trial would need to be a pragmatic real world trial. The exact type of trial and trial design are beyond the scope of this thesis. However, given the above issues regarding refining the intervention, fidelity of the facilitation, and scaling of the intervention, it would be premature to hold a definitive trial. Therefore, further pilot testing and a feasibility trial would be a more appropriate next step. The other key issue would be what the outcome measure for the impact of the intervention was. Other RCTs of complex interventions in general practice have reported limited outcomes.(286, 287) In the case of the 3D trial, which aimed to improve patient-centred general practice care for patients with multi-morbidity, there was an improvement in patient experience, but this was not the primary outcome measure, which was quality of life.(287) In comparison, Boivin’s intervention primary outcome measure was a process measure: whether more patient centred indicators were chosen.(101) An RCT of our intervention could focus on process measures such as voting differences in the card sort meeting, changes in the voting meeting, or whether the practice genuinely pursued different priorities in the action plan; or it could explore outcome measures such as whether patient experience improves as a result of the action plan, or even focus on longer term outcomes such as quality of life. All of these would need to be decided with the CRG. I would be interested in exploring whether the intervention has a transformative effect on the professionals and their relationships with patients, job satisfaction, and organisational culture. However, this research is about a complex intervention in a complex adaptive system, and as such an RCT may not be feasible or appropriate. (105, 106)

Finally, I would like to develop and refine the framework of the work of creating and maintaining participatory space. Many frameworks exist for supporting and evaluating PPI in research, and I have drawn on three participatory frameworks.(33, 36, 50, 288) However, none explore the work of stakeholders within the participatory space. The advantages of working with existing theory is that it can be refined and extended through use in different contexts, building a knowledge base.(139) I would like to explore whether our framework is transferable to other contexts and settings including other institutional and non-institutional participatory spaces. I would also be interested in exploring whether the framework can be used prospectively to plan participatory space, and by existing groups to evaluate their space, potentially as a precursor to changing it.

8.5 Conclusions

This thesis describes the process of working with a multi-stakeholder co-research group to develop an intervention to strengthen the role of patient participation in general practice service improvement. We have developed a theoretically informed intervention which resulted in more patient-centred service improvements. The core components of the intervention are:

- A bespoke, locally adaptable, prioritisation survey to consult the wider public. This can be administered within an individual general practice population, to survey patients' opinions about potential service improvements.
- A series of structured partnership meetings with patient PPG members and staff to adapt the survey and then develop an action plan based on the results. The meetings use participatory methods and facilitation to create a participatory space for shared organisational decision making.

We also developed a theoretically informed framework of the work required to create and maintain inclusive, equitable, and safe participatory space. This framework highlights that it is through this space that the transformative potential of patient participation is possible. Further work is required to understand whether this framework is transferable to other contexts where participatory space is created and maintained.

The intervention resulted in actions consistent with patient priorities for service change. However, several barriers have been identified, including a lack of opportunities to reflect, that warrant further attention to support implementation and the scope for long term change in how patients and staff work together. The policy of mandatory patient participation is unlikely to be successful unless patient participation work is recognised as a separate skill set and adequately resourced.

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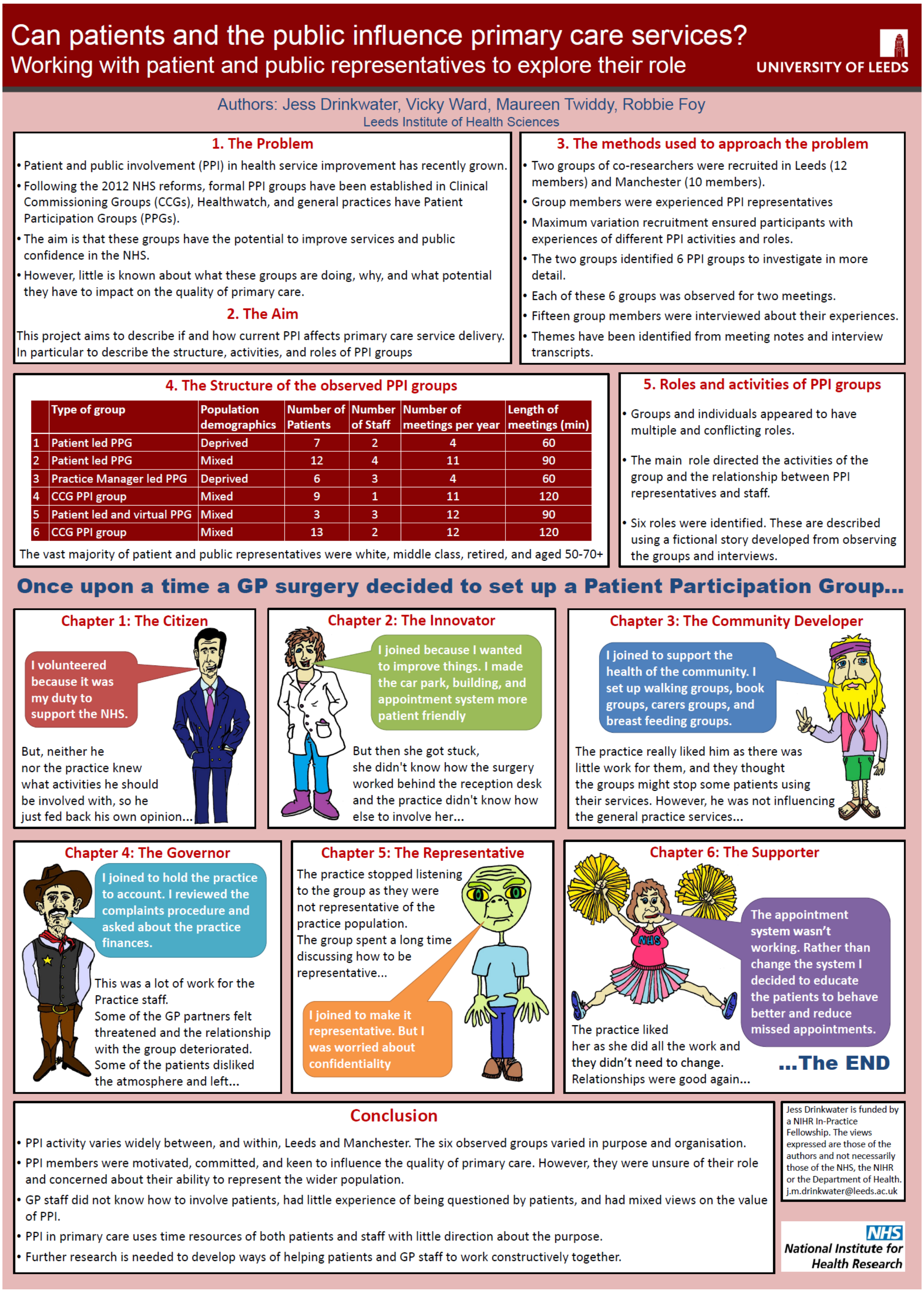
Appendix 1. INVOLVE Poster



Can patients and the public influence primary care services?

Working with patient and public representatives to explore their role

UNIVERSITY OF LEEDS

Authors: Jess Drinkwater, Vicky Ward, Maureen Twiddy, Robbie Foy
Leeds Institute of Health Sciences

1. The Problem

- Patient and public involvement (PPI) in health service improvement has recently grown.
- Following the 2012 NHS reforms, formal PPI groups have been established in Clinical Commissioning Groups (CCGs), Healthwatch, and general practices have Patient Participation Groups (PPGs).
- The aim is that these groups have the potential to improve services and public confidence in the NHS.
- However, little is known about what these groups are doing, why, and what potential they have to impact on the quality of primary care.

2. The Aim

This project aims to describe if and how current PPI affects primary care service delivery. In particular to describe the structure, activities, and roles of PPI groups

3. The methods used to approach the problem

- Two groups of co-researchers were recruited in Leeds (12 members) and Manchester (10 members).
- Group members were experienced PPI representatives
- Maximum variation recruitment ensured participants with experiences of different PPI activities and roles.
- The two groups identified 6 PPI groups to investigate in more detail.
- Each of these 6 groups was observed for two meetings.
- Fifteen group members were interviewed about their experiences.
- Themes have been identified from meeting notes and interview transcripts.

4. The Structure of the observed PPI groups

	Type of group	Population demographics	Number of Patients	Number of Staff	Number of meetings per year	Length of meetings (min)
1	Patient led PPG	Deprived	7	2	4	60
2	Patient led PPG	Mixed	12	4	11	90
3	Practice Manager led PPG	Deprived	6	3	4	60
4	CCG PPI group	Mixed	9	1	11	120
5	Patient led and virtual PPG	Mixed	3	3	12	90
6	CCG PPI group	Mixed	13	2	12	120

The vast majority of patient and public representatives were white, middle class, retired, and aged 50-70+

5. Roles and activities of PPI groups

- Groups and individuals appeared to have multiple and conflicting roles.
- The main role directed the activities of the group and the relationship between PPI representatives and staff.
- Six roles were identified. These are described using a fictional story developed from observing the groups and interviews.

Once upon a time a GP surgery decided to set up a Patient Participation Group…

Chapter 1: The Citizen

I volunteered because it was my duty to support the NHS.

But, neither he nor the practice knew what activities he should be involved with, so he just fed back his own opinion…

Chapter 2: The Innovator

I joined because I wanted to improve things. I made the car park, building, and appointment system more patient friendly

But then she got stuck, she didn't know how the surgery worked behind the reception desk and the practice didn't know how else to involve her…

Chapter 3: The Community Developer

I joined to support the health of the community. I set up walking groups, book groups, carers groups, and breast feeding groups.

The practice really liked him as there was little work for them, and they thought the groups might stop some patients using their services. However, he was not influencing the general practice services…

Chapter 4: The Governor

I joined to hold the practice to account. I reviewed the complaints procedure and asked about the practice finances.

This was a lot of work for the Practice staff. Some of the GP partners felt threatened and the relationship with the group deteriorated. Some of the patients disliked the atmosphere and left…

Chapter 5: The Representative

The practice stopped listening to the group as they were not representative of the practice population. The group spent a long time discussing how to be representative…

I joined to make it representative. But I was worried about confidentiality

Chapter 6: The Supporter

The appointment system wasn't working. Rather than change the system I decided to educate the patients to behave better and reduce missed appointments.

The practice liked her as she did all the work and they didn't need to change. Relationships were good again…

…The END

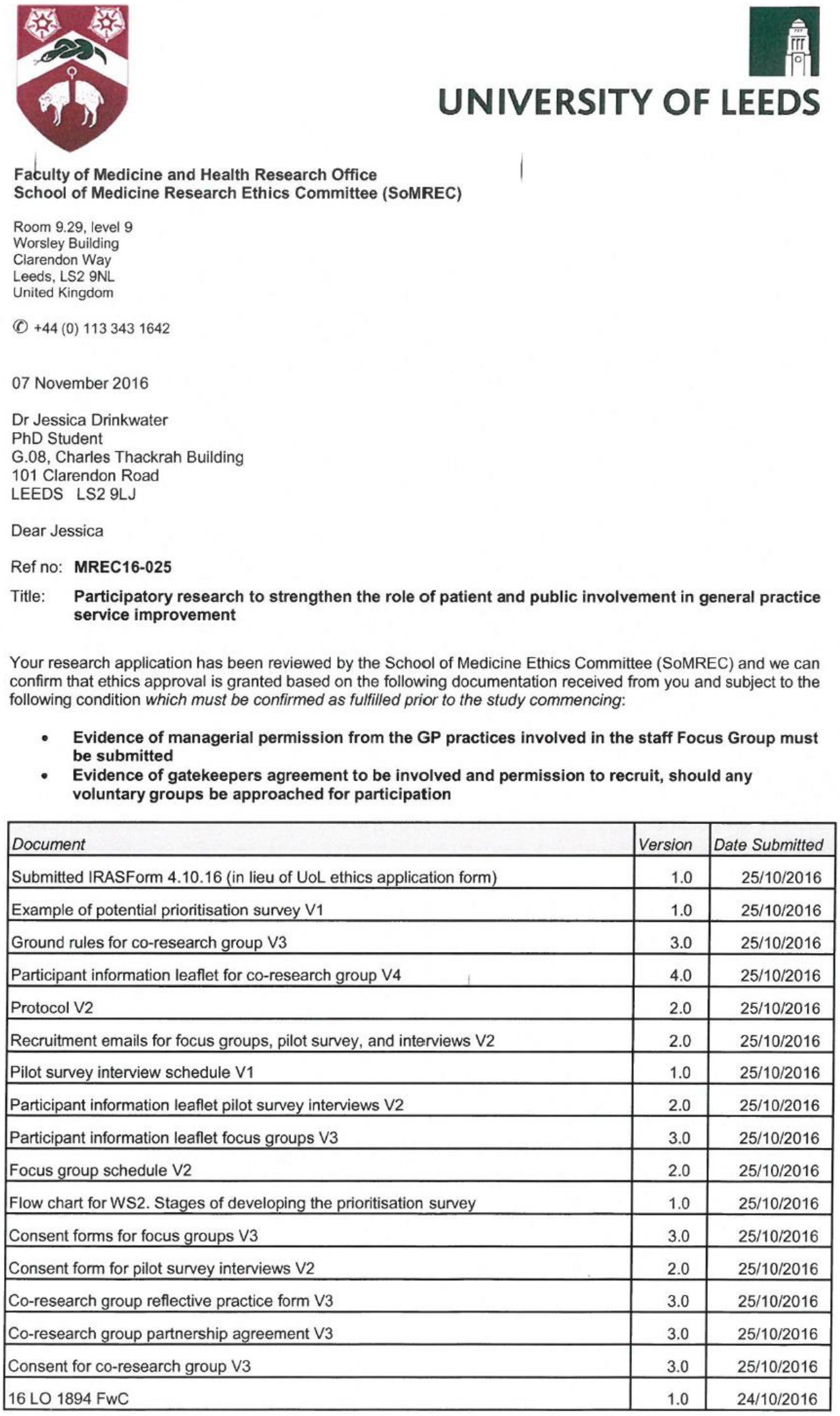
Conclusion

- PPI activity varies widely between, and within, Leeds and Manchester. The six observed groups varied in purpose and organisation.
- PPI members were motivated, committed, and keen to influence the quality of primary care. However, they were unsure of their role and concerned about their ability to represent the wider population.
- GP staff did not know how to involve patients, had little experience of being questioned by patients, and had mixed views on the value of PPI.
- PPI in primary care uses time resources of both patients and staff with little direction about the purpose.
- Further research is needed to develop ways of helping patients and GP staff to work constructively together.

Jess Drinkwater is funded by a NIHR In-Practice Fellowship. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.
j.m.drinkwater@leeds.ac.uk

NHS
National Institute for Health Research

Appendix 2. Ethical approval for co-research group and intervention development



UNIVERSITY OF LEEDS

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

Room 9.29, level 9
Worsley Building
Clarendon Way
Leeds, LS2 9NL
United Kingdom

✆ +44 (0) 113 343 1642

07 November 2016

Dr Jessica Drinkwater
PhD Student
G.08, Charles Thackrah Building
101 Clarendon Road
LEEDS   LS2 9LJ

Dear Jessica

Ref no: **MREC16-025**

Title: **Participatory research to strengthen the role of patient and public involvement in general practice service improvement**

Your research application has been reviewed by the School of Medicine Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documentation received from you and subject to the following condition *which must be confirmed as fulfilled prior to the study commencing*:

- **Evidence of managerial permission from the GP practices involved in the staff Focus Group must be submitted**
- **Evidence of gatekeepers agreement to be involved and permission to recruit, should any voluntary groups be approached for participation**

Document	*Version*	*Date Submitted*
Submitted IRASForm 4.10.16 (in lieu of UoL ethics application form)	1.0	25/10/2016
Example of potential prioritisation survey V1	1.0	25/10/2016
Ground rules for co-research group V3	3.0	25/10/2016
Participant information leaflet for co-research group V4	4.0	25/10/2016
Protocol V2	2.0	25/10/2016
Recruitment emails for focus groups, pilot survey, and interviews V2	2.0	25/10/2016
Pilot survey interview schedule V1	1.0	25/10/2016
Participant information leaflet pilot survey interviews V2	2.0	25/10/2016
Participant information leaflet focus groups V3	3.0	25/10/2016
Focus group schedule V2	2.0	25/10/2016
Flow chart for WS2. Stages of developing the prioritisation survey	1.0	25/10/2016
Consent forms for focus groups V3	3.0	25/10/2016
Consent form for pilot survey interviews V2	2.0	25/10/2016
Co-research group reflective practice form V3	3.0	25/10/2016
Co-research group partnership agreement V3	3.0	25/10/2016
Consent for co-research group V3	3.0	25/10/2016
16 LO 1894 FwC	1.0	24/10/2016

SL AR 2 Non CTIMP	1.0	24/10/2016

Please notify the committee if you intend to make any amendments to the original research ethics application or documentation. All changes must receive ethics approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you every success with the project.

Yours sincerely

Roger Parslow

Dr Roger Parslow
Co-Chair, SoMREC, University of Leeds

(Approval granted by Co-Chairs Dr Roger Parslow on behalf of committee)

Appendix 3. Participant information leaflet: Co-research group participants

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about?

The NHS is committed to finding new and better ways of working with patients and the public to improve healthcare services. Patient participation groups (PPGs) in each GP surgery are seen as a way of improving general practice services. But there is little evidence of what works. This study aims to design and test a clear role for PPGs in improving GP services.

Different stakeholders working with PPGs in general practice will come together as a group to do this research together.

This study aims to do four things:

1. Look at existing evidence of what works when involving patients in service improvement.
2. Design an intervention that can be used by PPGs to set priorities for service improvement in general practice.
3. Test the intervention in general practice to see whether it improves working relationships between staff and PPG members, as they work together to address the chosen service improvement priority.
4. Explore the challenges and benefits of working together as a multi-stakeholder group.

The study is being led by me, Jessica Drinkwater, as part of a National Institute for Health Research doctoral research fellowship. I am also a GP with an interest in how to support and develop PPGs.

Why have I been chosen?

Your experience of PPGs, general practice, and/or patient and public involvement (PPI) in service improvement is really important in shaping this project and developing an intervention that works for everyone. Stakeholders in Leeds and Manchester, have been invited to take part in the study.

What will I be asked to do if I take part?

If you decide to take part you will be invited to join a co-research group which will include GPs, practice managers, engagement staff, and patients and the public involved in PPGs or other service improvement activities related to general practice. Before you join the group I will be happy to meet with you individually to discuss any questions or concerns you may have and to explain the study in more detail.

The co-research group will meet for approximately 2-4 hours, four times a year for five years. Each year, two of these meetings will be in Leeds and two will be in Manchester, at a convenient location for all involved. At these meetings we will discuss the progress of the project and our reflections on the implications for PPGs. These meetings will provide opportunities to understand and influence what happens in the study. You will be asked to contribute to the discussion which will involve interactive tools such as drawing and labelling diagrams. Meetings will be recorded and I will make notes at the meetings which will be shared with the group.

Between meetings there will be opportunities to get involved in doing the research. This will involve joining smaller task and finish groups (which will also be recorded) and commenting on research documentation, helping with recruitment strategies, helping to facilitate focus groups, conducting interviews, analysing data and writing up results. To help with this we will communicate via email and you will also have access to a shared online space at the University of Leeds. What you get involved with depends on your interest, how much time you have, and your previous experience. Training will be provided about various aspects of the research methods as needed by myself or colleagues. I will also keep a diary about how we work together and this may include notes of discussions we have outside meetings and quotes from emails.

To explore the challenges and benefits of working together as a multi-stakeholder group you will be asked to reflect on your involvement after each meeting. Once a year you will be asked to share your learning and reflections with the rest of the group.

What happens to the data and how is confidentiality maintained?

All information collected during this study will be kept confidential. The audio-recordings of group meetings may be transcribed. Along with notes and diagrams from the meetings they will be anonymised so that any personal information (such as names, addresses, or places of work) will not be included in the research. Only I, and those people attending meetings, will have access to any personal information about you. All people attending meetings will be asked to keep personal information confidential. With your permission anonymous excerpts from transcripts, meeting notes, diagrams, and my diary, will be discussed at group meetings and may be used in reports and scientific publications. I will send you a summary of the results at the end of the study.

All the research data will be stored in a locked filing cabinet or on password protected computer files at the University of Leeds. The secure anonymous research data will be kept for three years after the study has ended, before being destroyed. During this time it may help shape future work. To help me understand and interpret the research data I will discuss the anonymised data with my academic supervisors at the Leeds Institute of Health Sciences and the University of Limerick. I could also be asked to show the anonymous research data to authorised people from regulatory bodies, for them to check that the study is being carried out properly. All information will be kept confidential unless there is disclosure of actual or intended harm to others. As a researcher I have obligations placed upon me by my professional code of conduct. In the unlikely event that comments made by you raise concerns of a criminal nature or about patient-safety and the quality of care you have received, these concerns would be escalated to relevant individuals and or organisations.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep, and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without harm to yourself. However, if you withdraw after participating in a meeting it will be difficult to remove all the data and therefore this may still be used anonymously.

Will I be paid for participating in the research?

Everyone in the co-research group will be paid £75 for attending meetings. For getting involved in other aspects of the research you will be paid at a rate of £150/day. This payment reflects that you are a member of the co-research team, that I am asking for a high level of involvement, and that your involvement is essential for the study to succeed. Refreshments will be provided at meetings and travel expenses will be paid so that you are not out of pocket.

There are unlikely to be any harmful effects of taking part in this study. However, the level of involvement is high. To reflect this there is no obligation to take part in extra activities and Wendy Hobson will provide admin support.

Who has given permission for the research?

This research has been approved by the University of Leeds Research Ethics Committee (Ref MREC16-025) and is funded by the National Institute for Health Research.

What if there is a problem?

If you are worried about the research or have any questions please speak to me. Alternatively you can contact my academic supervisor Professor Robbie Foy.

Jessica Drinkwater	Academic Supervisor for fellowship:
Researcher and GP	Professor Robbie Foy
Tel: (0113) 343 0868	Tel: (0113) 343 4879
Email: j.m.drinkwater@leeds.ac.uk	Email: r.foy@leeds.ac.uk

Thank you very much for taking time to read this information sheet

Appendix 4. Consent form: Co-research group participants

Researcher: Jessica Drinkwater

If you are happy to participate please complete and sign the consent form below

	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated 25/10/2016 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.	
I agree to take part in recorded meetings and notes being made during the meetings.	
I agree that anonymous transcripts, materials from the meetings, and notes can be stored securely for 3 years after the study has ended on University of Leeds computers	
I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research unless I wish to be. I agree to the use of anonymous quotes in study reports.	
I agree that the data collected from me, can be used in relevant future research in an anonymised form.	
I agree to treat confidentially the identity of other group members and any personal information discussed in group meetings. I will also treat confidentially anonymous data from interviews and focus groups.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 5. Co-researcher recruitment

Recruitment of co-researchers:

Recruitment to the group was through local networks of known individuals and opportunistic invitation to key stakeholders. See Appendix 6 for selection criteria. Many of these were subjective and therefore final recruitment decisions were discussed with my supervisors. See Table 2.1 for co-researcher characteristics, and Appendix 7 for attendance at meetings.

The majority of people were recruited from a previous study (Appendix 1).(75) In addition I invited two people who work for local involvement charities with a wider reach than PPGs, and one patient with history of being involved in general practice research, but no direct PPG involvement. GPs and practice managers were difficult to recruit. I advertised the opportunity to get involved through local newsletters, networks and personal contacts. Emails to networks resulted in one practice manager expressing interest, but never joining a meeting. Nurses very rarely attend PPGs. All six GPs were eventually contacted through personal contacts of mine, my supervisor, or co-researchers.

Appendix 6. Co-researchers selection criteria

Expectations of the stakeholder group and group members:

The group will involve both patients/the public and general practice staff and engagement workers. The group will be involved in all decisions about the project. There will also be opportunities to get involved in “doing” the research, but the main activity will be attending four 2-3 hour meetings per year (2 in Leeds and 2 in Manchester) and communicating via email between meetings. Travel expenses and an honorarium will be paid for work done.

Selection criteria for the stakeholder group:

Essential member characteristics	Must be able and willing to use and communicate by email.
	Enthusiastic and committed to getting involve.
	Have an interest in general practice.
	Able to work with other people (especially Jess Drinkwater).
	Must live or work in Manchester or Leeds.
	Happy/able to attend 4 meetings a year – times agreed by group agreement (but some may be in working hours and some outside working hours).
	Happy/able to travel to meetings: the venue will alternate between Leeds and Manchester (reasonable travel expenses will be paid) – may be able to consider Skyping into meetings.
	Awareness that this is a 5 year project – life events happen and interests change – but at the beginning be committed to 5 years.
	Happy to share and reflect on their experience of both PPGs and working as part of a mixed (staff, patient, researcher) group on this project (eg evaluation of the group work/function).
	Able to engage in constructive critical feedback and challenge – both challenging the group and having your ideas/perspective challenged (no personal challenge).
Desirable member characteristics	Part of an established network of people who are involved in PPGs/general practice or work with PPGs or the public to influence general practice.
	Happy to engage with their network, to test out ideas that come up during the project and feed information back to the group.
	Flexibility about meeting times (will be agreed by the group).
	Interested in and willing to contribute to the research process –focusing on both process and outcomes.
	Willing to get involved with some work outside meetings (within reason) for example email communication, reading papers/material, attending steering meetings (in addition to group meetings - once a year), conducting interviews, involvement in a systematic review, blogging, writing about the project. An honorarium will be provided.
Essential group characteristics (the group characteristics will be used to select members if there is a lot of interest)	Mix of people from Leeds and Manchester (aim 5 from each)
	Only one patient or member of staff per practice.
	Mix of members of the public, general practice staff, engagement staff.
	Mix of people with experience of high and low functioning PPGs and some with no experience of PPGs.
	Mix of enthusiasts and those who are sceptical about PPGs.
	Diversity (within reason) with regards to age, disability, gender, sex, sexuality, race, belief/religion, relationship status, pregnancy, and background.
	Mix of people with previous research experience and those without any research experience.

All members must agree to abide by the Terms of Reference and ground rules

Appendix 7. Co-researchers attendance at meetings

Initials	Role	M1	M2	M3	M4	TAFG1 M1	TAFG1 M2	TAFG1 M3	M5	TAFG2 M1	TAFG2 M2	M6	TAFG2 M3	TAFG2 M4	TAFG2 M5	M7	M8	M9	M10
MR	Patient	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X
MK	Patient	X	X		X	X	X	X	X	X		X	X	X	X	X	X	X	X
RC	Patient	X	X		X				X	X	X	X					X		X
DM	IC	X	X																
NB	Patient																		
AD	Patient	X	X	X			X	X		X		X	X	X	X	X	X		X
VBB	CCGEL	X	X																
SP	GP						X												
TF	GP			X	X							X							
RM	Patient	X	X		X	X	X	X	X	X	X	X	X	X	X	X	X		X
GP	Patient	X	X	X	X	X		X	X	X	X		X	X		X	X		X
RA	Patient	X																	
BD	Patient																		
MJ	Patient																		
PG	Patient			X	X				X		X		X	X	X		X		X
JP	IC	X	X																
GS	GP			X		X													
ZN	GP			X	X			X	X										
SL	PEL	X		X															
NH	GP															X	X		X
AH	GP																	X	

M1 = Meeting 1 etc; TAFG1:1 = Task and finish group 1 etc; X = indicates attended the meeting.

IC = Involvement Charity, CCGEL = Clinical Commissioning Group Engagement Lead, PEL = Practice Engagement Lead

Grey areas indicates a time when the individual had not started involvement with the study or had withdrawn from the study

After M10 membership remained stable, except AH attended infrequently and then stopped after M21

Appendix 8. Co-research group partnership agreement

Introduction

Patient Participation in Improving General Practice (PPIG) is a participatory research project. It has two aims:

- To develop an intervention to strengthen the role of patient and public involvement in general practice service improvement
- To explore the relationship between the public and general practice staff when they try to work together at an organisational level to develop services

The research project will form Jess Drinkwater's PhD thesis. It is funded by the National Institute for Health Research (NIHR) and there is a limited budget. This research project has been funded for 5 years.

Participatory research aims to work with all stakeholders involved with an issue, as equal partners in the research.

The stakeholders for this project are the public, Patient Participation Group (PPG) members, general practice staff (including clinicians and non-clinicians), general practice commissioners (CCGs and NHS England), engagement workers (NHS and voluntary sector), policy makers, and researchers.

Representatives from these stakeholder groups will work together as partners in a co-research group throughout the research process of this project. The research process includes developing the research question, designing the research methods, doing the research and collecting data, analysing and interpreting the data, and disseminating the results.

Each partner brings ideas and resources that come from their different experience, knowledge, expertise, and capabilities. Working together through cooperation, collaboration, trust and respect, the partners build a multidimensional view of the issue. This will significantly strengthen the project and the projects outcomes.

Purpose of this partnership agreement

The purpose of this partnership agreement is to set out the principles and procedures of how we will work together throughout the project to achieve our goals. How we work together must respect all our values and the scientific integrity of the research.

All partners have obligations towards the project and each other.

Principles

- We will respect each other and our values equally
- There will be opportunities for people to get involved with every aspect of the research
- All involvement is valued. Some people may have more resources (time, experience, networks ect) for involvement than others. We will aim for equitable involvement based on each individuals' resources.
- All partners will have opportunities to be involved in decision making throughout the project. All partners will have equal weight in decision making which will be consensual
- The research methods used must be scientifically robust.

- All partners must act ethically and respect the research ethical approval for the project.
- Confidentiality and anonymity of all individuals and organisations must be maintained unless individual parties choose to be named when the results are reported.
- Informed consent must be obtained from all partners and research participants without coercion. Any individual is free to stop being involved at any time.
- All partners have a duty to treat all information about the research and produced from the research in line with information governance policies at the University of Leeds
- All partners will be involved in interpreting and disseminating the results to ensure there is a clear message that everyone is happy with.
- The research must be relevant and aim for practical as well as traditional research outputs.

Rights and Responsibilities

All partners have the following responsibilities

- To do no harm and raise awareness of potential harm
- To uphold our principles and values throughout the project
- To respect one another and research participants, and all contributions from each other and research participants, even if we disagree.
- To avoid personal criticism, personalising disagreement, bullying or harassment. If this happens individuals will be asked to leave the group.

Jess Drinkwater's responsibilities

- To collaborate with all partners on all aspects of the research
- To support the other partners by
    - responding to questions and emails promptly,
    - arranging meetings in advance,
    - ensuring partners receive information in a timely manner,
    - ensuring partners receive enough information to contribute,
    - providing refreshments at meetings
    - ensuring people have enough information to stay up to date
- To support active involvement by all partners throughout the project by offering opportunities to get involved and outlining of the skills and experience needed, time involved in participating, and resources provided for participating
- To ensure that the research has the appropriate ethical approval, research governance, and information governance.
- To ensure the scientific quality of the research so that we produce credible research and outputs which are beneficial to all partners
- To promote the dissemination of the results of the research by all partners to different stakeholder networks
- To provide training or approach her supervisors to provide training to the group as needed and within reason.

Partner responsibilities

- To contribute as much as possible and represent the interests of different stakeholder groups.

- To collaborate in, and advise on the research process – designing the question, designing the research methods, collecting the data (including recruitment), and analysis and interpretation of the results
- To help to disseminate the results by making the content meaningful to our stakeholder groups and promoting the dissemination amongst our networks.
- To be responsible for being aware of our strengths and weaknesses and ask for clarification and/or training where necessary
- To try to attend as many meetings as possible and if we cannot attend to send apologies.
- To reflect on our involvement to help evaluate the partnership

University of Leeds responsibilities

- To provide payment and reimburse expenses.
- To provide administrative support (see below)

Rights of partners include

- To be treated with respect at all times by all partners
- To be valued and have our contribution valued
- To know the project aims and objectives, research methods, and results
- To ask questions at any time
- To know that we can withdraw from being involved in any part of the project or the whole project at any time without harm

How we will work together

- Co-research group meetings will be held approximately four times a year (two in Leeds and two in Manchester), minutes and agendas will be sent to all members in advance. Given the stop/start nature of research, will there be times when we need more/fewer meetings in one year.
- Task and finish groups will be set up comprised of co-research group partners to complete specific aspects of the research between meetings. There may be other opportunities to get involved. Partners are encouraged to get actively involved but within their limits of time, knowledge and experience.
- Partners will be encouraged to discuss issues between meetings by email and online discussion groups.
- Meeting times will be based on when the majority of people can attend. We will vary meeting times to allow everyone to attend some meetings.
- Jess Drinkwater will co-chair meetings with another partner. The other partner will be a revolving co-chair based on who is happy to volunteer for the role. The role of the co-chair will be:
  - To ensure meeting times are kept to
  - To give all the chance to contribute and ensure a balanced discussion
  - To stay in chair role for as much as possible (i.e. no personal views while chairing)
  - To ensure clear and specific outcomes and actions are agreed and actioned
- All partners will stick to meeting group ground rules which have been developed by the group

How we will make decisions together

We will aim for consensus agreement when making decisions.

If this cannot be achieved, we will vote. The vote will be carried if there is 70% agreement.

We have agreed not to set a quorate for meetings. If a decision is needed quickly we will accept the decision of those in attendance. If the decision is not urgent we will try to give everyone the opportunity to vote on decisions eg by email.

Conflicts of Interest

All partners have different, often multiple roles, and therefore have different interests and influences. We have agreed to keep an up-to-date list of who's who. This will include each partners self-declared different roles, so that their respective influences and interests are transparent. This list will be for people within the group only.

Conflict resolution

If conflict arises we will first try to address it within the group via consensus or voting. If this is not possible Jess Drinkwater will try to negotiate a solution. If the problem is still not resolved, or if the conflict is involving Jess Drinkwater, we will ask her supervisors to help negotiate resolution.

Dissemination content and audience

Dissemination content and the audience will be decided by the group. We will develop an advanced strategy of who to target with what content. Dissemination materials will be sent to the whole group before being shared with the public.

Authorship agreement

The group will be acknowledge in all dissemination activities. Individual contributions will be acknowledge where there has been significant individual involvement and they meet standard authorship criteria:

1. *Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND*
2. *Drafting the work or revising it critically for important intellectual content; AND*
3. *Final approval of the version to be published; AND*
4. *Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.*

Partnership evaluation

We agreed two elements to the evaluation:

a) Direct and immediate feedback during meetings. This will be achieved by having dedicated time at the end of each meeting and placing sticky notes with comments in an envelope
b) All partners will be encouraged to complete a reflective evaluation form after each meeting. These can be kept and used as individuals wish (eg local appraisal). We will discuss these once a year and share bits of them to see how things are going.

Group membership

- Membership of the co-research group is by invitation only and will be decided by the group
- Partners will commit to the project for 5 years. However, life events happen and priorities change, therefore group members will be able to leave at any time.
- We will decide together as a group whether it is appropriate to replace members who leave (details to be decided). Any new members will need an induction to the group

Support for partners

- Administrative support for the Partners will be provided by Wendy Hobson at Leeds Institute of Health Sciences – Tel: 0113 343 0837 or email: w.hobson@leeds.ac.uk
- Partners will be paid £75 for attending meetings and standard rate (not first class) travel expenses will be covered. Refreshments will be provided at meetings. Other expenses will not be covered, but could be discussed on a case by case basis with Jess Drinkwater.
- Partners will be paid at a rate of £150/day for work outside meetings and have travel expenses covered. Work outside meetings should be discussed with Jess Drinkwater before it is undertaken to ensure there is enough money in the budget to cover payment for this work.
- General support will be provided within the group and by Jess Drinkwater
- If a partner has a problem they will first discuss it with Jess Drinkwater or Wendy Hobson. If they are not happy to do this, or the problem is not resolved, they can contact her primary supervisor – Robbie Foy – on R.Foy@leeds.ac.uk

Many thanks to PRIMER for letting me see their terms of reference, and the Kahnawake Schools Diabetes Prevention Project for letting me see and use some of their Code of Research Ethics, to base some of the content of this partnership agreement.

Appendix 9. Participant information leaflet: Focus groups

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about?

The NHS is committed to finding new and better ways of working with patients and the public to improve healthcare services. Patient participation groups (PPGs) in each GP surgery are seen as a way of improving general practice services. But there is little evidence of what works. This study aims to design and test a clear role for PPGs in improving GP services.

The first step in improving GP services is prioritising what needs to be improved. This study aims to discover what parts of general practice patients and staff can work together to improve. This will be used to develop a survey to collect patients' views of the priorities for service improvement in their local general practice. This can then be used by PPGs in lots of different practices.

The study is being led by me, Jessica Drinkwater, as part of a National Institute for Health Research doctoral research fellowship. I am also a GP with an interest in how to support and develop PPGs. I am leading this collaborative project assisted by co-researchers who are members of the public, patients, engagement staff, practice managers and GPs

Why have I been invited?

We are interested in finding out what different groups of people think are the key parts of general practice that patients and staff can work on to improve together. We are asking different PPGs, community groups, and groups of staff what they think. We are looking for a wide variety of viewpoints from all those who are involved in using or working in general practice. Your group is one of approximately 6 groups we will be talking to in Leeds and Manchester.

What will I be asked to do if I take part?

I will be asking everyone in your group if they are happy to take part. If you all agree to take part, I would like to come to one of your meetings with another member of our co-research group. At this meeting we will present some different statements about parts of general practice. We will ask your group to discuss these and comment on whether you think they are important, and whether you think patients can be involved in making changes to them. We would also like to get your feedback on a draft outline of a survey that the statements will be used in. We would like to check that it makes sense and is easy for PPGs to use. The meeting will be audio recorded. The meeting length will depend on how much everyone has to say and will probably take between 1 and 2 hours. We will be happy to come to a meeting that is convenient for your group and we can be flexible with timing to fit in with your agenda. I will lead the meeting with help from a member of the co-research group.

What happens to the data and how is confidentiality maintained?

All information collected during this study will be kept confidential. The audio-recordings of the meeting will be transcribed and anonymised so that any personal information (such as names, addresses, or places of work) will not be included in the research. To help me understand and interpret the research data I will discuss the anonymised data with my academic supervisors at the Leeds Institute of Health Sciences and University of Limerick. Quotes from the focus groups will be discussed with the co-research group who are helping with the research. Quotes will also be used in reports, presentations, and scientific publications. No one outside the project will be allowed access to the original recordings. I will send you a summary of the results at the end of the study.

All the research data will be stored in a locked filing cabinet or on password protected computer files at the University of Leeds. The secure anonymous research data will be kept for three years after the study has ended, before being destroyed. During this time it may help shape future work. I could also be asked to show the anonymous research data to authorised people from regulatory bodies, for them to check that the study is being carried out properly. All information will be kept confidential unless there is disclosure of actual or intended harm to others. As a researcher I have obligations placed upon me by my professional code of conduct. In the unlikely event that comments made by you raise concerns of a criminal nature or about patient-safety and the quality of care you have received, these concerns would be escalated to relevant individuals and or organisations.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep, and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without harm to yourself. However, if you withdraw after participating in a meeting it will be difficult to remove all the data and therefore this may still be used anonymously. If you do not wish to take part, I will not meet with your group and there will be no harmful effects to your group.

What are the benefits and risks of participating in the research?

There are no immediate benefits or risks to taking part in this study. The data collected will be used to develop a prioritisation survey to be used by PPGs to improve general practice services. There is no payment for taking part in this research, but to say thank you I will provide refreshments for the meeting and a certificate of taking part if you would like one. We also hope that the content of this focus group will be of interest to your group.

Who has given permission for the research?

This research has been approved by the University of Leeds Research Ethics Committee (Ref MREC16-025) and is funded by the National Institute for Health Research.

What if there is a problem?

If you are worried about the research or have any questions please speak to me. Alternatively you can contact my academic supervisor Professor Robbie Foy.

Jessica Drinkwater	Academic Supervisor for fellowship:
Researcher and GP	Professor Robbie Foy
Tel: (0113) 343 0868	Tel: (0113) 343 4879
Email: j.m.drinkwater@leeds.ac.uk	Email: r.foy@leeds.ac.uk

Thank you very much for taking time to read this information sheet.

Appendix 10. Consent form: Focus group participants

Researcher: Jessica Drinkwater

If you are happy to participate please complete and sign the consent form below

	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated 25/10/2016 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences.	
I agree that the focus group can be audio-recorded.	
I agree that anonymous transcriptions of my interviews can be stored securely for 3 years after the study has ended on University of Leeds computers.	
I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I agree to the use of anonymous quotes in study reports.	
I give my permission for anonymous quotes to be shared with the co-research group who are helping with the research.	
I agree that the data collected from me can be used in relevant future research in an anonymised form.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 11. Participant information leaflet: Pilot survey interview participants

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about?

The NHS is committed to involving patients in how services, including general practice, are designed and run. With my research group I have developed a survey to collect general practice patients' views of the priorities for service improvement in their local general practice.

This study aims to explore how people understand this survey and how easy or difficult it is to fill in.

The study is being led by me, Jessica Drinkwater, as part of a National Institute for Health Research doctoral research fellowship. I am also a GP with an interest in patient involvement. I am leading this collaborative project assisted by co-researchers who are members of the public, patients, engagement staff, practice managers and GPs

Why have I been invited?

You have been invited to take part because, as a member of the public registered with a general practice, you are the target audience for this survey.

What will I be asked to do if I take part?

If you decide to take part, we would like you to complete the survey. We may also ask you to be interviewed whilst you complete the survey. If you take part in an interview we will ask you to try to think out loud about how and why you are answering each question. At the end of the survey we will ask you what you thought of the survey and if you have any feedback. Completing the survey and the interview will take place at the University of Leeds or a place convenient for you. It will be at a time of your choosing. If you are interviewed it will be by me or one of the members of the co-research team. The interview will be audio-recorded using a digital recorder. The survey takes about 10-20 minutes to complete. The length of the interview will vary, depending on how much you wish to talk about and how much time you can spare. However, it is likely to be about 30 minutes.

What happens to the data and how is confidentiality maintained?

All information collected during this study will be kept confidential. The audio-recording of the interview will be transcribed and anonymised so that any personal information (such as names, addresses, or places of work) will not be included in the research. Your survey answers will be anonymised and, together with other people's responses, analysed using statistical software. To help me understand and interpret the research data I will discuss the anonymised data with my academic supervisors at the Leeds Institute of Health Sciences and University of Limerick. Quotes from the interview will be discussed with the co-research group who are helping with the research. Quotes will also be used in reports, presentations, and scientific publications. No one outside the project will be allowed access to the original recordings. I will send you a summary of the results at the end of the study.

All the research data will be stored in a locked filing cabinet or on password protected computer files at the University of Leeds. The secure anonymous research data will be kept for three years after the study has ended, before being destroyed. During this time it may help shape future work. I could also be asked to show the anonymous research data to authorised people from regulatory bodies, for them to check that the study is being carried out properly. All information will be kept confidential unless there is disclosure of actual or intended harm to others. As a researcher I have obligations placed upon me by my professional code of conduct. In the unlikely event that comments made by you raise concerns of a criminal nature or about patient-safety and the quality of care you have received, these concerns would be escalated to relevant individuals and or organisations.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. Completing the survey indicates that you are happy to take part and your responses can be used for this research. If you agree to an interview you will also be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without harm to yourself.

What are the benefits and risks of participating in the research?

There are no immediate benefits or risks to taking part in this study. The data collected will be used to make sure that the survey is easy to understand, asks what you think it is asking, and is useful. We may make changes to the survey based on your answers before we try it out in general practice.

Will I be paid for participating in the research?

You will be paid £10 for completing the survey and a total of £30 for completing the survey and taking part in an interview. This is to compensate you for taking time out to get involved.

Who has given permission for the research?

This research has been approved by the University of Leeds Research Ethics Committee (Ref MREC16-025) and is funded by the National Institute for Health Research.

What if there is a problem?

If you are worried about the research or have any questions please speak to me. Alternatively you can contact my academic supervisor Professor Robbie Foy.

Jessica Drinkwater	Academic Supervisor for fellowship:
Researcher and GP	Professor Robbie Foy
Tel: (0113) 343 0868	Tel: (0113) 343 4879
Email: j.m.drinkwater@leeds.ac.uk	Email: r.foy@leeds.ac.uk

Thank you very much for taking time to read this information sheet.

Appendix 12. Consent form: Pilot survey interviews

Researcher: [enter name of research who is conducting the interview]

If you are happy to participate please complete and sign the consent form below

	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated 25/10/2016 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences.	
I agree that the interview can be audio-recorded.	
I agree that anonymous transcriptions of my interviews can be stored securely for 3 years after the study has ended on University of Leeds computers.	
I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I agree to the use of anonymous quotes in study reports.	
I give my permission for anonymous quotes to be shared with the co-research group who are helping with the research.	
I agree that the data collected from me can be used in relevant future research in an anonymised form.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 13. A description of the process

Who we are:

We are a group of patients, GPs, general practice staff, and researchers interested in making patient involvement in primary care meaningful and effective.

What we want to do:

We want to help your patient participation group (PPG) develop the part it plays within your general practice.

One role of PPGs is to be involved in improving general practice services. We are developing a tool to support this. We hope using this will mean patients' opinions and ideas are taken as seriously and valued as equally as the opinions and ideas of the professionals who care for you.

How we are going to do this:

Our tool helps PPGs to get involved in improving services by finding out what is most important to the wider patient population about how care is provided at your general practice.

It will show what patients think is most important about their care, rather than what their actual experience is. By asking patients what they value the most, the survey is honest and open about the fact that they cannot have everything.

The tool is a survey which is flexible to what is happening in your practice, the needs of your practice, and your practice population.

It is a two stage process:

- Stage 1: The PPG and practice staff decide what goes into the survey;
- Stage 2: The survey asks the wider patient population to choose between different imaginary services that they would most like to experience. This allows us to calculate what features of general practice the patient population value the most.

How the tool works:

We will give the PPG and practice a list of features of general practice which can be used in a survey. The features of general practice on the list can be changed to be flexible to your practice so that they provide realistic options to your patient population.

The PPG and practice need to decide together which 5 features will go into the survey. It is important that they agree on this to make sure the survey is acceptable to both the practice and the PPG. This discussion itself may help the practice and PPG to explore what they can achieve together.

You need to pick features from the list which are relevant to your practice and can realistically be changed. This will mean the time and work you put into the survey will lead to a result that you can act on. It will also mean that the survey is offering patients a real opportunity to influence how your general practice works.

The survey will ask patients to pick between pairs of imaginary examples of a general practice service. They will be asked to choose the one that they prefer the most. The imaginary examples will include different levels for the 5 features of general practice you choose. By varying these imaginary examples and asking as many people as possible to choose between different pairs of imaginary examples, we can calculate the features of general practice that are most important to your patient population.

The tool consists of 10 steps:

- Step 1: The PPG and practice staff will be shown features of general practice where service improvement could occur. The list of features have been selected through a long and rigorous process involving patients, general practice staff and researchers.
- Step 2: The PPG and practice discuss the features.
- Step 3: The PPG and practice together agree the top 5 features they would like to put forward to their patient population. You should choose your top 5 thinking about what is important to the practice, what is feasible to act on, and what other resources are around to support changes in these areas.
- Step 4: The top 5 features are turned into a survey unique to your practice by our research group.
- Step 5: The PPG and the practice agree how the survey will be conducted: online; on paper in the practice; a weblink sent out by text message; a ballot box in waiting room; an iPad.
- Step 6: The PPG carry out the survey.
- Step 7: Our research group will analyse your survey responses for you.
- Step 8: The PPG and practice meet together to discuss the results and plan changes you would like to make.
- Step 9: The PPG and practice make changes or explain why change cannot happen.
- Step 10: The PPG and practice publicise the results of the survey and the resulting action or inaction with an explanation of why nothing happened.

Appendix 14. TIDieR checklist for describing the intervention (194)

<table>
<tr><td colspan="2">1. Brief name</td></tr>
<tr><td colspan="2">Patient participation in general practice service improvement</td></tr>
<tr><td colspan="2">2. Why the intervention is needed</td></tr>
<tr><td colspan="2">Patient participation is recognised as important internationally and supported by successive UK governments.(1, 5, 7) However, the terminology, meaning and purpose of participation are contested and variably interpreted (10, 11) and lack of evidence of impact may suggest meaningful participation is not occurring.(23)
This intervention outlines the theoretical and practical elements required to strengthen patient participation in general practice patient participation groups (PPGs).
The intervention is based on three theoretical constructs developed from previous research; (101, 102)
• All stakeholders have multiple credible and different knowledge to contribute. All different forms of knowledge (experiential, presentational, propositional and practical) are valued.
• All stakeholders have legitimate roles. Representational legitimacy of patients and staff is increased through different approaches to representation (statistical, democratic, and symbolic) and a focus on inclusivity.
• Power differentials exist within and between different stakeholder groups. Deliberative partnership meetings should aim for equity of voice.
This intervention conceptualises PPGs as participatory action research groups, utilising action research cycles as a structured approach to change.</td></tr>
<tr><td colspan="2">3. What materials are needed for the intervention</td></tr>
<tr><td colspan="2">A list of 24 features of general practice turned into physical hand held cards. One card per attribute. Green, orange, and red paper to group the cards depending on whether they are priorities for service improvement in the practice or not. Used in meetings 1a&b.</td></tr>
<tr><td colspan="2">Voting sheets for PPG members to vote on their top five attributes. Used in meeting 2.</td></tr>
<tr><td colspan="2">An adaptable discrete choice experiment (the survey). The survey includes instructions on how to complete it; a series of between 1-5 choice tasks; demographic questions; free text space; and an advertisement for the PPG. Each survey will be adapted to the local practice.</td></tr>
<tr><td colspan="2">The survey is available in three physical formats: a paper version with three choice tasks; an online version with five choice tasks; and a voting box version with one choice task.</td></tr>
<tr><td colspan="2">A training guide to support PPGs to distribute the survey.</td></tr>
<tr><td colspan="2">Materials to promote inclusive discussion of the results of the survey. Used in meeting 3.</td></tr>
<tr><td colspan="2">4. What procedures will happen during the intervention</td></tr>
<tr><td colspan="2">Each PPG will participate in the following meetings:</td></tr>
<tr><td>Meeting 0:
patients & staff</td><td>Introduce the project and CRG to the PPG</td></tr>
<tr><td>Meeting 1a:
patients only
Meeting 1b:
staff only</td><td>Meeting participants take it in turns to read out the 24 cards. The group decide the category of the card:
‘yes, you’d be interested to know what patients think’ (green), ‘maybe’ (orange),
‘no, we wouldn’t be interested or would not be prepared to change the feature’ (red).
Meeting finishes with review of the categories.
Speed evaluation (sticky notes used to say whether the meeting was ‘good’ or ‘bad’, and why)</td></tr>
<tr><td>Meeting 2:
patients & staff</td><td>‘Green’ and ‘orange’ category cards from meeting 1a&b discussed.
All participants vote individually on their top 5 attributes using a voting sheet.</td></tr>
</table>

	Each person has one minute to discuss their voting. Scores are combined and discussed. Repeat voting. The five features with the combined highest score are chosen. Speed evaluation
Training meeting: aimed at patients, staff welcome	All participants complete the survey to experience filling it in. Discussion of the survey Demonstration of handing out the survey using CRG members. Practical opportunity to role play in small groups. Feedback and reflections Discussion of practical issues around survey distribution Speed evaluation
Meeting 3: patients & staff	Survey results sent out before the meeting for individual reflection. PPG members reflect on distributing the survey. Presentation of results and discussion. Action planning using flexible brainstorm (participants write ideas on sticky notes which are displayed on the wall and grouped together) Speed evaluation
Survey distribution: the survey will be distributed by the PPG working with the practice who will be encouraged to reflect on the experience.	
5. Who will deliver the intervention	
All meetings will be facilitated by two members of the co-research group; Jess Drinkwater and another member.	
The PPG and practice will distribute the survey. Jess Drinkwater will analyse the results.	
6. How will the intervention be delivered	
The intervention will be implemented in two general practices, staggered over time.	
Meeting dates, times, and lengths of meetings will be negotiated with each practice. Recommended meeting lengths are 60-90 minutes.	
There are three survey formats with different delivery mechanisms	The paper and ballot box survey will be completed in the waiting room.
	The online survey can be completed on a tablet computer in the waiting room, or distributed as a weblink on the practice website or sent out via text message.
7. Where will the intervention be delivered	
Meetings	Meetings will take place in the usual PPG/practice meeting venue, usually within the general practice.
The survey	The ballot box survey will be displayed in the waiting room. It will need two boxes, voting sheets, and a notice board to show instructions.
	The paper survey will be distributed in the waiting room, patients can take it home to complete.
	The online survey will be completed at a time and place convenient for the respondent.
8. When will the intervention be delivered	
Timings are approximate and may vary between PPGs	Meetings 0, 1a, 1b, and 2 will happen in month one and two.
	The survey will be open for two to three months. Each practice will receive 100 paper surveys to complete. Online and voting box survey responses will be unlimited.
	Meeting 3 will happen in month four or five of the intervention
9. Tailoring of the intervention	
The timing and length of meetings, and who participates, can be tailored to the practice's normal ways of working. Basic expectations are that meetings will include at least 3 patients and one GP.	

The fixed aspects of the intervention are the number of meetings; the structure and content of the meetings (discuss features of primary care separately, vote together, and discuss results); and the need to do the survey.
The survey will be tailored to each individual practice, including the features used in it and the practice name and logo. Each practice can choose one survey format or any combination to distribute the survey.
10. Modifications to the intervention
The intervention is still in a testing phase and will likely be further modified following evaluation in two general practices.
11. and 12. How well the intervention was delivered – fidelity
The intervention, including fidelity, will be evaluated in two general practices using an ethnographic approach.

Appendix 15. Flowchart of field testing activities

Flowchart describing what is involved in the project. Version 1

Timings	**Expected activities of PPG and practice staff**	**Research team activity**
	Meeting 0: Initial meeting Content: Meet each other. Explain project Outcome: Agree involvement	
Month 1	**Meeting 1a: Agree priority short list** Participants: PPG patients only Content: Card sort: 24 features of general practice Outcome: Short list of features to put in survey	Meetings facilitated and observed by research team. Survey adapted for the practice by the research team
	Meeting 1b: Agree priority short list Participants: Practice staff Content: Card sort: 24 features of general practice Outcome: Short list of features to put in survey	
	Meeting 2: Vote on priorities Participants: PPG patients and practice staff Content: Combine both short lists & vote on final 5 Outcome: 5 features agreed for survey	
Month 2-3	**Distribute survey** Patient population to complete survey PPG attend training and help with distribution	Training to use survey & ongoing support
Month 4	**Meeting 3: Discussion of results** Participants: PPG patients and practice staff Content: Discuss results and develop an action plan Outcome: Action plan	Results analysed, & meeting facilitated & observed by research team
Month 5-12 Depends on how often PPG usually meet. Maximum follow up for 4 meetings or up to month 12.	**Meeting 4: PPG meeting** Participants: Decided by PPG and practice staff Content: Decided by PPG and practice staff Outcome: Decided by PPG and practice staff	Research team will observe meetings. No Facilitation. **Individual interviews with 3-5 members of PPG and 2-3 members of staff - may be at different time points.**
	Meeting 5: PPG meeting Participants: Decided by PPG and practice staff Content: Decided by PPG and practice staff Outcome: Decided by PPG and practice staff	
	Meeting 6: PPG meeting Participants: Decided by PPG and practice staff Content: Decided by PPG and practice staff Outcome: Decided by PPG and practice staff	
	Meeting 7: PPG meeting Participants: Decided by PPG and practice staff Content: Decided by PPG and practice staff Outcome: Decided by PPG and practice staff	

Appendix 16. General practice DCE review – search strategy

Aim:

To identify how stated preference methods have been used in general practice service design and delivery. This will influence the design of the prioritisation survey

Objectives:

- To describe the benefits and challenges of different experimental designs
- To identify attributes and levels that have been used in previous stated preference experiments in general practice

Methods:

Search terms have been developed based on previous systematic reviews of stated preference methods and primary care

Databases:

- Medline via OVID
- EMBASE via OVID
- HMIC via OVID

Eligibility criteria:

- Topic: Stated preference methods used in general practice service design, delivery, and improvement. To compare different attributes within general practice
- Study type: Stated preference experiment studies (comparing different attributes of general practice services with each other – NOT with other services eg GP versus hospital)
- Language: English language full text available
- Year of publication: 1980 to present, based on trends of stated preference methods use

Exclusion criteria:

- Where the context is general practice, but the stated preference experiment is not about general practice services eg medical careers; using general practice population to investigate preferences for other services (eg hospital versus general practice). Can include preferences of patients with a specific disease/characteristic and their preferences for different attributes in general practice, but not preference for clinical treatments.
- Where another service is conducted within general practice eg screening, but the experiment is about the other service (breast screening) and not general practice. Or where the experiment is about a specific disease/condition management programme within general practice.
- Doctors preferences about medical services.
- Decision making at an individual patient clinical decision (medication, treatment, screening – ie not comparing service attributes)

Data extraction:

Narrative synthesis of similar designs;

List of attributes and levels;

Quality control

Search strategy for Medline and Embase:

1 primary care.tw.
2 exp General Practice/
3 general practi*.tw.
4 GP.tw.
5 general practitioners/ or physicians, family/ or physicians, primary care/
6 Nurse Practitioners/ or Primary Care Nursing/
7 family doctor*.tw.
8 family practice.tw.
9 primary medical care.tw.
10 family medicine.tw.
11 family physician*.tw.
12 primary health care/
13 or/1-12
14 discrete choice.tw.
15 stated preference*.tw.
16 Stated choice.tw.
17 (choice or preference*) adj1 (experiment* or scenario* or set or analysis or exercise).tw.
18 conjoint adj1 (analysis or experiment* or measurement or stud*).tw.
19 (paired comparison* or pairwise choice* or functional measurement or part-worth utilities).tw.
20 Best worst.tw.
21 Maxdiff.tw.
22 Dichotomous choice.tw.
23 Contingent adj1 (valuation or weighting).tw.
24 Willingness to pay.tw.
25 Ranking exercise.tw.
26 Trade off.tw.
27 Standard gamble.tw.
28 measure of value.tw.
29 or/14-28
30 13 and 29

Search strategy for Health Management Information Consortium (HMIC)

1 primary care.tw.
2 general practi$.tw.
3 GP.tw.
4 Nurse Practi$.tw.
5 Primary Care Nurs$.tw.
6 family doctor$.tw.
7 family practice.tw.
8 primary medical care.tw.
9 family medicine.tw.
10 family physician$.tw.
11 primary health care.tw.
12 or/1-11
13 discrete choice$.tw.
14 stated preference$.tw.

15 Stated choice.tw.
16 (choice or preference$) adj1 (experiment$ or scenario$ or set or analysis or exercise).tw.
17 conjoint adj1 (analysis or experiment$ or measurement or stud$).tw.
18 (paired comparison$ or pairwise choice$ or functional measurement or part-worth utilities).tw.
19 Best worst.tw.
20 Maxdiff.tw.
21 Dichotomous choice.tw.
22 (Contingent adj1 (valu$ or weight$)).tw.
23 Willingness to pay.tw.
24 Ranking exercise.tw.
25 Trade off.tw.
26 Standard gamble$.tw.
27 measure of value.tw.
28 or/13-27
29 12 and 28

Appendix 17. General practice DCE review – table of papers

	Author	Year	Location	Aim and context	DCE development work	DCE design	Survey design	Most important attribute
1	Ahmed, A. Fincham, J. E. (227, 228)	2010 2011	USA Georgia	Investigate population preferences for Retail clinics with nurses over the doctors' office. Policy context of increasing retail clinics	No information on development of attributes and levels. No pilot	3 attributes 2*3 levels 2 clinical scenarios. Full factorial design 16 tasks. ? alternative traded off – rated yes or no.	Computer aided telephone interview to internet panel representative of the local area. Response rate 33.1% - 493	Appointment wait period (preferences varied by symptoms)
2	Boonen, L. H. Donkers, B. Schut, F. T. (223)	2011	Netherlands	Investigate population preferences for services. To help insurance companies develop channelling strategies (incentives and disincentives) to get patients to use different services	Literature review of patient preferences. Consultation with health insurers, pharmacies, and the Dutch GP association. Focus on realistic choices for attributes and levels. Piloted – no details	8 attributes 2*5, 3*1, 4*2 levels 2 survey versions (co-pay vs. discount). 3 unlabelled alternatives. Status quo option in 2 tasks. D-optimal design. 14 tasks per person.	Internet survey with representative panel. Survey included: demographics, current service utilisation, attributes of current service, patient preferences for attributes, pharmacy DCE. Response rate 80% - 1907	Extended telephone access (status quo bias – preferred own practice)
3	Caldow, J. Bond, C. Ryan, M. Campbell, N. C.	2007	UK Scotland	Investigate the acceptability of Practice Nurse vs. Doctor led treatment for minor illness.	Literature review and focus groups regarding important factors when patients consult.	5 attributes 2*2, 3*1, 4*2 levels 3 unlabelled alternatives. Opt out in 3 qs	Postal survey, sent from 22 general practices. Survey included: experience of surgery visit, demographics,	Who you see – doctor or nurse

	Miguel, F. S. Kiger, A. Lee, A. (210)			Policy context of increased use of practice nurses	Pilot on 50 people and test-retest validity checked on 43 people in focus group	Fractional factorial design. 8 tasks per person	satisfaction with the last appointment, attitudes and perceptions towards doctor/nurse-led care, and preferences for doctor/nurse-led care. Response rate 49% - 1343	
4	Cheraghi-Sohi, S. Hole, A. R. Mead, N. McDonald, R. Whalley, D. Bower, P. Roland, M. (198, 199, 209)	2007 2007 2008	UK Manchester	Investigate patients' priorities for the organisation of the consultation. Policy context of delivering patient centred care.	Literature review of the attributes of primary care. Pilot study with 'think aloud' qualitative interviews and quantitative pilot on 30 people to test survey properties	2 surveys: generic and patient centred. 3 symptom scenarios (2 in each survey) 6 attributes each (9 total) 2*7, 4*2 levels. 2 unlabelled alternatives. No opt out D-efficient design 18 tasks (2 sets of 8 plus 2 to test consistency)	Postal survey sent from 6 general practices. No other details about survey. Response rate: 53% - 1193	Thorough physical examination (preferences varied by type of appointment)
5	Danyliv, A Pavlova, M Gryga, I Groot, W (224)	2015	Ukraine	Investigate population preferences for the organisation of out-patient (including primary care) services, including cost	Literature review of previous primary care DCEs. Pilot on 55 people	8 attributes 2*7, 3*1 levels 2 unlabelled alternatives, one fixed throughout to represent current practice.	In person interviews sampled from nationally representative household survey Survey included:	Attitude of medical staff

				Contribute evidence of ‘consumer’ preferences to national policy on healthcare reform		Orthogonal main-effect fractional factorial design. 16 tasks	Demographics; health status; any medical education Response rate not calculated – 303	
6	Gerard, K. Lattimer, V. (211)	2005	UK England	Investigate patients’ preferences for characteristics of emergency primary care services during the day. Policy context of new services to provide urgent day time services.	Literature review. Review of national and local policy initiatives Steering committee advice Interviews with key stakeholders (no further info) Piloted (no info)	6 attributes 3*6 levels 2 unlabelled alternatives. No opt out No information on the design of the choice tasks 10 tasks	Paper survey handed out/posted out to patients attending day time emergency care appointments. Included: demographics, experience of emergency care and health services generally, current health, and ease of survey Response rate: 71% - 432	Being kept informed about waiting time.
7	Gerard, K. Salisbury, C. Street, D. Pope, C. Baxter, H. (212)	2008	UK England	Investigate patients’ preferences for booking appointments. Policy context of increasing speed of access to routine GP appointments	Literature review including policy documents. 7 semi-structured interviews with patients. Pilot survey with 29 people – qualitative and quantitatively analysed	4 attributes 2*2, 3*1, 4*1 levels 2 symptom scenarios 2 unlabelled alternatives. No opt out D-efficient design 8 tasks (4 for each symptom scenario)	Paper survey handed out by receptionists in 8 general practices. Survey included: info on today’s appointment, plausibility of the attribute levels used, two internal consistency checks, demographics,	Seeing a doctor of choice

							and current health status. Response rate: 94% - 1052	
8	Gerard, K Tinelli, M Latter, S (213)	2014	UK	Investigate patients' preferences for doctor vs. nurse prescribing in minor illness. Nurse prescribing is a potential policy solution to increasing access to medicine	Literature review. Expertise within the research team. National patient survey data on nurse prescribing and GP satisfaction. Pilot on 12 people - quantitative	4 attributes 2*2, 4*2 levels (different for doctor/nurse) 3 labelled alternatives (doctor, nurse, do nothing). Orthogonal fractional factorial design. 5 tasks (1 to check internal consistency)	Paper survey handed out by receptionists in 5 general practices. Survey included: demographics, current health, and use of primary care services. Response rate: 451 responses (unable to monitor response rate)	Consulting own doctor (relational continuity)
9	Gerard, K. Tinelli, M. Latter, S. Blenkinsopp, A. Smith, A. (214)	2012	UK	Investigate patients' preferences for who prescribes medication for long term conditions. Non-doctor prescribing is a potential policy solution to increasing access to medicine	Research teams interpretation "generic characteristics" known to be important and tailored for the context of non medical prescribing. Used national survey data to define levels Pilot on 12 people – quantitative	4 attributes 2*3, 4*1 levels 3 labelled alternatives (prescribing pharmacist, "own doctor," "available doctor"(scenario fixed throughout)) No opt out. Orthogonal fractional factorial design.	Paper survey handed out by receptionists in 5 general practices. Survey included: Demographics experience of general practice, health status, experience of non medical prescribers, use of prescriptions, expectations of being prescribed medication today.	Consulting own doctor

						5 tasks (1 to check internal consistency)	Response rate: 451 responses (unable to monitor response rate)	
10	Haas, M. (230)	2005	Australia Sydney	Investigate population preferences for non-health attributes of care within a general practice consultation. To explore why people change GP	Qualitative research – no further details	7 attributes 2*5, 4*2 levels 4 survey versions with different reasons for attending GP. 3 labelled alternatives (current GP (specified in first part of survey), hypothetical GP, or another GP (unspecified). Design not specified 24 tasks	Paper survey delivered to random sample by market research company (had to have been to GP in last 6mths). Survey included: Evaluation of their most recent GP visit against the attributes of interest, demographics, health care utilisation. Response rate: 88% - 128	Trust in provider
11	Hjelmgren, J. Anell, A. (225)	2007	Sweden	Investigate why patients choose different primary care models – in particular individual doctor vs. primary care team. National debate over models of primary care.	Literature and policy review. Pilot for clarity on 15 people	5 attributes 2*3, 3*1, 4*1 levels 2 unlabelled alternatives. No opt out Fractional design with fold over. 4 tasks	Randomly allocated postal survey. Survey included: Demographics, health status (EQ-5D), health care utilisation, experience of primary care services, rating of attributes 58% - 928	Influence over the care received

12	Lagarde, M. Erens, B. Mays, N. (215)	2015	UK England	Investigate factors which influence patients’ registration with a general practice. New policy to allow patients more flexible registration outside of one geographical area.	Literature review of NHS policy interventions to improve access to general practice. RCT of a pilot to allow patients to register out of area and why they choose to do this. Pilot with 10 people followed by interview debrief. Second Pilot with 68 people quantitatively analysed to produce priors	6 attributes 2*4, 3*1, 4*1 levels 2 labelled alternatives ('practice in your neighbourhood'; 'practice outside your neighbourhood') No opt out Orthogonal experimental design for pilot then Bayesian D-efficient experimental design. 16 tasks.	Internet survey with representative existing market research panel. Survey included: Demographics, satisfaction with current GP and services offered by practice, primary care utilisation, health status. Response rate not calculated. 1706 responses analysed	Waiting time for appointment
13	Longo, M. F. Cohen, D. R. Hood, K. Edwards, A. Robling, M. Elwyn, G. Russell, I. T. (216)	2006	UK Wales	Investigate patients’ preferences for the characteristics of a ‘successful’ consultation. In particular shared decision making and risk communication. Context of a RCT of GP communication skills education	Literature review of shared decision making and risk communication. The first 74 surveys were considered a pilot	5 attributes 2*3, 3*2 levels 2 alternatives – one was constant throughout No opt out. D-efficient design. 14 tasks.	Postal survey sent to patients taking part in RCT (20 general practices). Patients had to have one of 4 symptoms. Survey sent 6mth after appointment. Survey included: Ranking of all attributes, experience of last consultation, ease of completing survey, time	Doctor listens

							taken to complete survey. Response rate: 78% - 565	
14	McAteer, A. Yi, D. Watson, V. Norwood, P. Ryan, M. Hannaford, P. C. Elliott, A. M. (217)	2015	UK	Investigate patients' care seeking behaviour and explore which service attributes effect decisions to seek care. Context of developing interventions to encourage efficient health care utilisation	A symptom survey	6 attributes 2*1, 4*2, 6*2, 8*1 levels. 3 symptoms (diarrhoea, dizziness, chest pain) 3 unlabelled alternatives, one do nothing. D efficient design with restrictions to ensure realistic choices 24 tasks (8 per symptom)	Postal survey to 1370 patients (across 20 general practices) who completed previous survey and agreed to be contacted again. Little info on what survey included, respondents asked to rate the seriousness of the 3 symptoms. Response rate: 63.1 – 851	Waiting time for appointment (differed by symptoms)
15	Pedersen, L. B. Kjaer, T. Kragstrup, J. Gyrd-Hansen, D. (119)	2012	Denmark	Investigate population preferences for the organisational aspects of general practice and compare these with GPs perceptions of patients' preferences. Context of agency relationship between doctors and patients	Literature of attributes of primary care (including previous DCEs). Qualitative interviews with GPS and patients. Practice visits. Focus groups with policy maker GPs.	7 attributes 2*2, 4*5 levels 2 unlabelled alternatives. Tasks completed twice, one forced choice, and one with opt out. Bayesian efficient main effects design.	Internet survey with representative panel. Survey included: Use of and satisfaction with GP, information about the levels of each attribute in current practice, demographics. Response rate not calculated – 698	Waiting time for appointment

					Piloted on 28 people to check understanding	4 tasks (but repeated twice so 8)		
16	Rubin, G. Bate, A. George, A. Shackley, P. Hall, N. (218)	2006	UK	Investigate patient preferences when making a routine appointment for a GP. Policy context of increasing speed of access to routine GP appointments	Literature review. Discussion with patients and GPs. Pilot with 63 people from a single practice - tested comprehension, ease of completion, and test-retest stability	3 attributes 2*2, 4*1 levels 2 unlabelled alternatives No opt out. Orthogonal design with dominance excluded. 7 tasks	Paper survey handed out in 6 general practices. Survey included: Demographics, previously validated items on reason for appointment. Response rate: 55.2% - 1153	Choice of doctor (difference between adult and child)
17	Scott A, Vick S (219)	1999	UK Scotland	Investigate patient preferences for attributes of the doctor-patient relationship within the consultation. Context of increased promotion of shared decision making as a feature of patient centred care.	Literature review of patient satisfaction with general practice. Heavily influenced by prior study (see 21)	5 attributes 2*4, 4*1 levels 2 survey versions with different symptom scenarios (mild/sever low back pain). 2 unlabelled alternatives No opt out Full factorial design. One non dominated alternative constant throughout. 8 tasks	Postal survey randomly sent to 125 patients at each of 35 general practices. Survey included: Demographics; health state; attitudes towards changing doctors (consumerism); past experiences - whether had low back pain before and last GP visit in terms of attributes. Response rate: 18.4% - 734	Being able to talk to the doctor
18	Seghieri, C. Mengoni, A. Nuti, S.	2014	Italy Tuscany	Investigate population preferences for	Literature review. Semi-structured interviews with	3 attributes 3*3 levels	Computer aided telephone survey with representative panel.	Own GP (continuity of care)

	(226)			different models of primary care. National debate over models of primary care specifically around individual versus team models.	primary care managers. Focus groups with patients to validate attributes and levels. Pre-pilot on 34 people to test opt-out and internal consistency Second pilot on further 34 people	2 unlabelled alternatives. No opt out. Full factorial design - paired using systematic level changes to protect orthogonality. 4 tasks	Survey included: patient experience and satisfaction; ranking of attributes; current health status; demographics. Response rate: 47% - 3372	
19	Tinelli, M. Nikoloski, Z. Kumpunen, S. Knai, C. Pribakovic Brinovec, R. Warren, E. Wittgens, K. Dickmann, P. (222)	2015	Europe: Germany Slovenia England	Investigate and compare patient preferences for general practice consultations across Europe. Pan-European policy priority of understanding and increasing patient choice.	Literature review of previous DCEs. Discussion with the research team, experts, patients, and their representatives. Feasibility pilot with 57 people With in-person survey approach, resulted in new survey. Pilot attributes and levels with further 36 people. A further test of the first 15 people in each country	5 attributes 4*5 levels 3 unlabelled alternatives – one status quo. D-optimal approach 5 tasks (1 dominated to check internal consistency). Vignette was a non-urgent issue	Paper survey handed out in 9 (2 German, 3 English, 4 Slovenian) general practices. Survey included: Describe 'current GP practice' in terms of the attributes and assign levels; demographics; health status; health care use. Response rate: 82% - 692	Best care (status quo bias – preferred own practice)
20	Turner, D. Tarrant, C. Windridge, K.	2007	UK	Investigate patients' preference for continuity of care compared with other	Qualitative semi-structured interviews with patients and carers about their	4 attributes 2*3, 4*1 levels 3 symptom scenarios.	Postal survey to patients at 9 general practices. 20 non-English speakers	See a person who has information about your

	Bryan, S. Boulton, M. Freeman, G. Baker, R. (220)			aspects of a primary care consultation. Policy context of increasing speed of access to routine GP appointments - concern about the effect on continuity of care	priorities for using primary care services. List of attributes reviewed by members of the research team. Piloted with 28 people, 16 interviewed	2 unlabelled alternatives. No opt out Fractional factorial design. 14 tasks (7 each for 2 of the 3 symptom scenarios)	completed survey through interview in practice. Survey included: Health status, health care utilisation, demographics Response rate: 47% - 646	medical history. (preference varied by type of appointment)
21	Vick, S Scott, A (221)	1998	UK Aberdeen	Investigate patient preferences for attributes of the doctor-patient relationship within the consultation. Context of increased promotion of shared decision making as a feature of patient centred care.	Literature review	6 attributes 2*4, 3*2 levels 2 survey versions with different symptom scenarios (mild/sever low back pain). 2 unlabelled alternatives No opt out Fractional factorial design. One non dominated alternative constant throughout. 13 tasks	Paper survey handed out in general practice. Survey included: Rating of each attribute; ease of survey; time to complete survey; demographics; health state; attitudes towards changing doctors (consumerism); what they would be doing if not at the doctor (to understand willingness to wait) Response rate: 63% - 101	Being able to talk to the doctor
22	Zickafoose, J. S. DeCamp, L. R. Prosser, A. (229)	2015	USA	Investigate parents' preferences for features of enhanced access to primary care.	Literature review of medical home programs to identify attributes of enhanced access.	8 attributes 2*2, 3*1, 4*5 levels 2 unlabelled alternatives No opt out	Internet survey with nationally representative panel. Oversampled for non-white respondents. Survey included:	Waiting time for appointment

				New policy emphasis on advanced access to improve care.	Discussion with paediatricians and primary care managers. Qualitative interviews with parents. Pilot - 20 parents – ‘think aloud’ qualitative interviews. Pre-test on 122 parents	Fractional factorial design 8 tasks	All children in family demographics, and parent-reported child health. Parents asked to complete survey for 1 child Response rate: 41.2% - 820 parents	

Appendix 18. General practice DCE review – table of attributes and levels

Attribute	Level	No. Studies
Price Cost of appointment to patient Co-payment or Discount User charges (per visit) Size of patient payment	\$59; \$75 £0; 8; 18; 28 £ 1, 3, 5, 7.5, 15, 25, 40, 75 Co-pay: 0; 3; 6; 9: Discount: 0; 3; 6; 9 euro 0; 100; 200; 300 SEK 20; 60; 100 euro out of pocket	6
Form of patient payment	Informal payment; Formal payment	1
Appointment wait time Number of days waiting for an appointment Waiting time for non-emergency visit Waiting time between contact and getting advice Length of time in days booked in advance for an appointment How quickly you can normally be seen by a GP in this practice Typical waiting time to the appointment (with a nonacute problem) Time to appointment Booking time Waiting time for consultation Sick visits Checkups and physicals Accessibility Waiting time for visit	Same day; Wait 1 day or more Same day; Next day; 2 days; 5 days 0 hrs; 1hr; 6hrs; 1day; 3days; 8days 2; 4; 7 days 0; 2; 4; 8 days Less than 2 days; 2 days of more 4.5 hours; 2.5 hours; 0.5 hours Same day (within 24 hours); Next day (within 48 hours; 5 days later; 10 days later Same day; Next day; A few days later; A week or more Same day; 3 days; 1 week; 2 weeks Same day; Within 48 hours; In 4 days; In 10 days Next day; Within one week; Within 2 weeks You are seen on the same day; You wait two days for the consultation; You wait five days for the consultation; You wait 10 days for the consultation Rarely the same day, usually in 1 to 2 days; Usually on the same day but may be asked to wait 1 to 2 days, depending on how sick child is; Always on the same day if requested; Walk in on a first-come, first-seve basis Usually available within same day to 1 wk; Usually available within 1 to 2 wk; Usually available within 2 to 4 wk; Usually available within 4 to 8 wk Next day at surgery (nurse prescriber); Next day at Walk in clinic (nurse prescriber); 2 days later at surgery (doctor); Next day at surgery (doctor) 0; 9; 180 minutes	17
Typical waiting time on the telephone	1; 5; 15; 30 minutes	1

Waiting time in front of the office Typical waiting time in the waiting room Waiting time	10; 45 min 5; 10; 20; 30 min 15; 20; 30 minutes	3
Distance from your home address to the GP Travel time Where patient is when advice given	5; 15; 25; 35 min 15; 60 min 0 miles (at home); 5 miles; 15 miles 5; 15; 30; 45 min 1; 5; 15; 30 km	5
Care setting-clinician combinations	Physician at a private practice; Nurse practitioner at a clinic within a supermarket, discount store, or chain pharmacy	1
Practice assistants available Physicians specialisation Who you see Who gives the advice Who booked to see Who performs routine tasks (eg blood samples, tests for allergies, vaccination) Who you consult	Yes; No General practitioner (district/family doctor/internist); Medical specialist A doctor; A practice nurse Doctor; Nurse; None of the above (paramedic) Nurse; Doctor, any availabile (not of choice); Doctor of choice GP; Nurse You consult a GP; You consult a nurse	7
Length of consultation Time available for consultation/treatment Length of appointment in minutes Average time allocated to the consultation Length of time	5; 10; 20; 30 min 10; 20 minutes 10; 20; 30; 40 minutes (nurse prescriber): 5; 10; 15; 20 minutes (doctor) 5; 10; 15; 20 min Less than 10 minutes; More than 10 minutes 5; 10; 15min	8
Being able to talk to the doctor Professional's attention paid to your views on your problme/medicine(s) Attention paid by professional to your views about medicines Doctor listens Being able to talk to the GP	The doctor does not seem to listen to what you have to say; The doctor seems to listen to what you have to say Appears to listen; Appears not to listen Appears not to listen; Appears to listen Doctor does not seem to listen; Doctor seems to listen GP does not listen; GP listens	5
Eliciting patient ideas Doctor takes notice of what you say about your health (legitimation)	The doctor is interested in your own ideas about what is wrong; The doctor is not interested in your own ideas about what is wrong Yes; No	2

Doctor's explanation of information Professional's words and explanations about your medicine How easily the information is understood GP's words and explanations	The doctor's words and explanations are difficult to understand; The doctor's words and explanations are easy to understand Difficult to understand; Easy to understand	4
Information about your health problem and its treatment Information you want Amount of infomration about your health problem and its treatment Information about your health problem Information about your treatment Doctor gives you information	The doctor gives you a lot of information Always; Most of the times; Rarely/Never The doctor give you a little information; A small amount; A moderate amount; A large amount A lot; A little If you ask for it; Whether you ask for it or not; Only about where you can get information; No	6
Doctors interpersonal manner Attitude of medical staff Doctor treats you with dignity (dignity) Doctor is trustworthy (trust in doctor)	Warm and friendly; Formal and Buisnesslike Polite treatment of medical staff; Arrogant treatment of medical staff Yes; No	4
Doctor's knowledge of the patient Continuity of helth professional Choice of doctor Relationship Continuity	The doctor has access to your medical notes and knows you well; The doctor has access to your medical notes but does not know you well Yes; No Your choice of doctor; With any available doctor Who you do not know; Who you know and trust See the same physician for nearly all checkups and some sick visits; See whoever is available for well and sick visits	5
Information	Who has information about your full medical history; Who does not have information about your full medical history	1

Shared decision-making Patient influence over care recieved Who chooses the treatment Listened to and involved in decision making Doctor accepts your decisions about your health	The doctor involves you in decsions about treatment; The doctor does not involve you in decisions about treatment Large influence; Limited influence The doctor chooses the treatment for you; The doctor chooses the treatment considering your opinion; You and the doctor make a joint decision; You choose considering the doctor's opinion Always; Most of the times; Rarely/Never Doctor chooses; You choose; Both choose GP; Joint; You Yes; Yes, but also gives advice/opinion; No, but tells you about his/her decision; No	7
Likelihood of having illness cured	75%; 80%; 85%	1
Chance of a satisfactory outcome	Poor chance; Fair chance; Good chance; Very good chance	1
Best care	Always; Most of the times; Rarely/Never	1
Certificate of Quality	No quality certificate; Yes, a quality certificate	1
Quality of contact with service	Not enough time with service to deal with problem, and interruptions; Enough time, but interruptions; Enough time, no interruptions	1
Practice type Primary care work model Primary care provider	Solo practice; Pharmacy and GP; Primary care centre Registration with GP; Registration with primary care team One's own GP; A primary care team (GP+other professionals); Another GP in the same practice	3
Choice for individuals	Individual choice of provider (GP or team); No choice	1
Choice of appointment times	One appointment offered; Choice of appointment times offered	1
Thoroughness of physical examination	The doctor gives you a thorough physical examination; The doctor's physical examination is not very thorough	1
Biopsychosocial perspective	The doctor asks about your social and emotional well-being as well as physical symptoms; The doctor asks about your physical symptoms only	1
Doctor recognises your pain/distress (support for emotional distress)	Yes; No	1

Extended telephone access Making contact through two or more telephone calls or if integrated with NHS Direct, one call, else in person to nearest ambulatory facility Communication outside office visits	Yes; No Single call; In person; Neither of above Telephone advice only during office hours and no email; Telephone advice 24h, 7 d/wk and no email; Telephone advice 24h, 7 d/wk and nonurgent email; Telephone advice 24h, 7 d/wk and urgent and nonurgent email	3
Convienience/availability Whether the practice is open on Saturday and Sunday morning (8am-12pm) Whether the practice is open at lunchtime (12-2pm) Whether the practice has extended opening hours - either 7-8am or 6-8pm Opening hours (besides normal opening hours) Weekday hours Late hours Weekend hours	Normal working hours only; Normal working hours and out of hours (evenings and weekends) Yes; No Yes; sometimes; never No extended opening hours; Open on Saturdays 3 Full days and 2 half days a week; 5 full days a week No office hours after 5 pm; 2 Evenings per wk, 5 to 8 PM; 4 Evenings per wk; 5 to 8 PM 5 Evenings per wk; 5 to 8 PM No weekend hours; Half day on Saturday; Full day on Saturday; Half days on Saturday and Sunday	8
Informed of expected wait	No information; Some information; Full information	1
Help offered by professional	Only advice provided; Diagnosis and advice provided	1
Doctor reassures you (reassurance)	Yes; No	1
Health review covers	High blood pressure only; High blood pressure and review of overall health	1
Whether the practice meets your specific health needs	Yes; No	1
How well the practice knows the health care services (eg hospital, community nurses ect)	The practice has previous experience with most of the health care providers in your neighbourhood; The practice does not have previous experience with most of the health care providers in your neighbourhood	1
Action you take	Self care; Practice nurse; NHS24/NHS Direct; Pharmacist; Complementary practitioner; GP	1
Diagnostic facilities	A lot of diagnostic facilities; Some diagnostic facilities; A few diagnositic facilities	1
State of the medical equipment	Modern medical equipment; Outdated medical equipment	1
Maintenance of the office	Old-looking physician’s office; Renovated physician’s office	1

Appendix 19. All attributes developed by the co-research group

The initials in the right hand column indicate co-researchers who voted for the attribute in their top 10 priorities.

Involvement

My general practice involve patients in how the practice is run

1	My general practice welcome feedback and actively try to get feedback from patients in many different ways.	
2	My general practice has an active patient participation group. They support the group but encourage the patients to take control. They seek advice from the patient group and share their plans (including business plan) with the patient group	GP, MK, RC, GS
3	My general practice involve patients when they are recruiting new staff	

Inter-personal care (how my general practice treats me)

Professionalism – attitudes, respect, behaviour, confidentiality, advocacy

At my general practice all the staff are clearly caring and respectful

4	It is clear that the doctors and nurses care about me as an individual and want to help me be healthy	TF, MK, AD
5	My general practice provide me with help to communicate if English is not my first language	RM
6	My general practice provides a confidential space for me to talk and be listened to	ZN
7	The doctors and nurses are polite, friendly and treat me with respect, they do not judge me	
8	All the staff are aware how the community in which I live might support 1 limit my health and the decisions I make about my health.	
9	My doctors work to promote and protect the health and rights of me and my community	PG
10	All the staff at my general practice are polite, friendly, helpful, and treat me with respect, they do not judge me	GP, RC, GS
11	The receptionists respect my privacy and my decisions about who I want to see. They do not ask me about personal details when other people can hear.	
12	My doctors and nurses respect my personal space during consultations	
13	My doctors and nurses respect my privacy and dignity during physical examinations	PG

Communication – listening, speaking, reading, writing, body language

It is easy to talk to people and get the information I need at my general practice

14	My doctors and nurses are interested in finding out about me	
15	There is clear information that I can understand about how my general practice works	MK, GS
16	The receptionists are friendly, chatty, and easy to talk to	PG
17	There is clear information that I can understand about prescriptions, how to order them, what they cost, and how to get a repeat prescription	
18	My doctors and nurses listen to what I say	PG, AD
19	The receptionists and management staff listen to what I say	
20	My doctors and nurses have a warm and friendly manner (not formal and business-like)	

Patient centred

The doctors and nurses at my general practice treat me as an individual

21	I get written information about my condition, that is specific to me, that is clear, and that I can understand	
22	My doctor is interested in my ideas about my treatment and happy to discuss these with me	
23	My doctor explains the different treatment options available to me, the benefits and harms of each option, and helps me to come to a decision about my treatment	MR, GP, TF, AD, MK, RC, RM
24	My doctors and nurses are interested in me as a person and my life (not just an illness or disease)	
25	My doctors and nurses ask me about my social and emotional wellbeing as well as my physical symptoms	
26	My general practice offers a range of different treatments and services. Including drugs, information, advice, peer support, community groups, financial and social support, and activities to help me stay healthy and prevent me from getting unwell.	
27	My doctors and nurses do not judge the decisions I make about my treatment and are open to discussing alternative therapies.	AD
28	My doctors and nurses will spend longer with me if this is important	ZN
29	My doctors and nurses words and explanations are easy to understand	
30	My doctors and nurses are interested in my ideas about what is wrong with me	

Access (how I access my general practice)

Personalised access

My general practice recognises me as an individual and is flexible about how I use the service

31	My general practice offers a range of appointment times that fit with my health needs and the other parts of my life (work, school, family)	ZN
32	My general practice offers a range of ways of contacting a doctor or nurse (face-to-face, telephone, online)	
33	I can plan appointments in advance, to fit in with the other parts of my life (work, school, family), to review my existing health problems	RC
34	I am involved in deciding how often, and how (face-to-face, telephone, online) my existing health problems are reviewed	
35	My practice work with me to reduce the number of visits I have to make to the general practice. For example by offering blood tests on the same day as appointments where possible so I don’t have to come back.	
36	My general practice are flexible about the length of appointment I can have with the doctor or nurse	

Access

It is easy to make an appointment to see someone or get help from my general practice

37	My general practice is open at times when I want to see a doctor or nurse	ZN
38	If I have an urgent problem I can drop in and wait to see a doctor	MK
39	It is easy to make an appointment at my general practice	MR, PG
40	I can make an appointment face-to-face, by telephone, or online	
41	It is easy to get through to someone at my general practice by phone	
42	There are lots of ways to contact my general practice, for example by phone, face-to-face, by email, Skype, online, or by text	GP, RC
43	I have access to my personal electronic record online	

44	My general practice tell me about significant test results or new diagnosis face-to-face rather than online	
45	My general practice offers home visits if I cannot get to the practice in person	PG
46	My general practice offers many different services such as being able to see a physiotherapist, pharmacist, dietician, and psychologist, as well as or instead of a GP or nurse	
47	I do not have to pay to use any services at my general practice	RM
48	There are doctors and nurses in my general practice who have different strengths and interests. The general practice make this clear so I can make a decision about who to see.	TF
49	My general practice can prescribe social activities (exercise, social groups, financial support) if we think it might help me live well	MR
50	My general practice is close to where I live	
51	It is easy to join my general practice and easy to leave whenever I want	
52	I can get an appointment to see a doctor within 24 hours	
53	I don’t have to wait a long time in the waiting room after my appointment is due	
54	I can easily get through to the receptionists by phone at my general practice	

Equality of access

My general practice cares about helping people who find it difficult to get help

55	My general practice put the most work and resources into the patients in my practice with the worse health and those who are least likely to ask for help.	TF
56	My general practice is flexible and treats people according to their need rather than their status	
57	My general practice tries to employ people who represent my local population as that I can relate to them	
58	My general practice help me to avoid hidden costs which might stop me getting help. They: • Do not have an expensive telephone number • They give me advice over the telephone so I don’t have to travel • If I do have to travel I can get an appointment during the day when I can use my free bus pass • The general practice make sure that everything can be done whilst I am there and I don’t have to keep coming back for more appointments	

Continuity (My general practice is stable & I know what to expect from them)

With an individual

I know what to expect from my doctor/nurse

59	I know and understand my doctor and nurse and they know and understand me	
60	I have a relationship with my doctor and nurse	
61	I have a named doctor or nurse who I see regularly	

With the practice

I know what to expect from my general practice

62	I know what to expect from my general practice , they don't keep changing things, this helps me plan my healthcare	
63	I know the reception and admin staff at my general practice and they know and understand me	
64	There is always a familiar and friendly face when I go to my general practice	

Information continuity

My general practice take care to record information about me and my care

65	My doctors and nurses have access to my medical notes and know me and my history	MR, TF, AD, RC, GS
66	My general practice gets my discharge letter and completes any work within it promptly	

Long term care (over time)

My general practice is permanent and I know what to expect over time

67	My doctor and nurse and I have a longstanding trusting relationship	PG, TF
68	I am confident I will be able to see the same doctor/nurse for all my health needs over a number of years	
69	My doctor and nurse has known me for a long period of time	
70	I have to see different doctors or nurses for different problems and treatments (eg blood test) at my general practice	
71	The doctors at my general practice are not permanent and may work at different general practices	

Consistency

I know to expect the same standard of care from everyone at my general practice

72	I can choose which doctor or nurse I see	TF, RC
73	All the staff at my general practice know the policies and how things work (like prescriptions). They all give me the same information about practice policies and how things work	
74	The doctors and nurses at my general practice all give me the same advice	

Co-ordination of care (my general practice helps me organise my care with other people and services involved)

Practice led

My general practice take responsibility for helping to organise my care

75	My general practice help me manage my health by reminding me about appointments and checking I am OK if I miss appointments	
76	My doctor knows about people, activities, and services, local to me that might be able to help me live well and encourages me to use these services if they might help	RM
77	My doctor and general practice work closely with all the other people and services involved in my health care. This helps to avoid mistakes, means I don't have to repeat myself, and helps everyone to know what is important to me and my health.	GP, MR, MK, AD, RM, GS
78	All the staff in my general practice work together as a team	PG
79	My general practice knows the carers (people, family, friends, paid carers) who care for and about me.	

80	My general practice involves me in decisions about which carers are involved in my care and what information they can have about me and my care.	
81	My general practice works with and supports my carers to look after me and help me live well.	
82	My doctor and nurse finds out what has happened to me after they have referred me to another service	
83	My general practice actively help and support me to avoid getting unwell, rather than waiting for me to become ill	MR
84	My general practice is part of a larger group of practices that provide lots of different services (it is not single handed) and work together	PG

Patient led

My general practice encourage me to plan and organise my own care

85	My general practice give me (or help me find) the information, skills, and resources that I need to manage my own health.	ZN, RC
86	My doctor and nurse encourage me and give me the confidence to manage my own health	MK

Trust

I trust my general practice and the staff that work there

87	I trust my general practice to act in my best interest and put me and my health first	TF, MR, PG
88	I trust my doctor/nurse to act in my best interest and put me and my health first	AD
89	I trust how the practice works and that it is designed in the best interests of me and other patients	GS

Hotel

My general practice care about the physical environment of the general practice

90	My general practice is in a warm, clean, and tidy building	TF, GP
91	My general practice is in a welcoming building.	
92	In my general practice there is information on the walls which I can read, is useful, and is tidy and regularly updated	
93	My general practice provide water and healthy food in the waiting room	
94	My general practice opens before the first appointment so you don't have to wait outside	
95	All the staff at my general practice are dressed smartly	
96	In my general practice the waiting room is comfortable and there is entertainment for me and my family (music, information, toys, reading material)	
97	It is easy and safe to park at my general practice	
98	My general practice makes it easy for me to know who I am talking to and what their role is.	
99	The staff have name badges and there are photos of all the staff up in the practice and online.	

Outcome

I am happy with the care I receive at my general practice

100	My doctor is able to tell me what is wrong with me within one (or two) appointments	
101	My doctor can give me treatment or refer me to someone who can quickly	
102	After I see my doctor, I am happy with the information (diagnosis), advice, referral, drugs, or other treatment they have given me	GP, MR
103	My doctor and nurse help me to avoid getting ill	
104	My doctor and nurse help me to stay healthy to maximise my quality of life	
105	It is likely I will be cured after seeing my doctor or nurse	
106	I am satisfied with the outcome of my visit to my general practice	MK, ZN
107	I receive the best treatment and care from my general practice	GS

Competence (I think the care I receive from my general practice is good)

Of the practice

I have confidence in the standard of care I get from my general practice

108	My general practice have a process of checking that all their patients are getting the best treatment according to national guidance.	
109	My general practice want to know if something goes wrong so they can learn from this. They let me know that they will investigate the problem, and tell me and the rest of the patients about what they did to make sure it doesn’t happen again.	MK, MR, AD, ZN, RM
110	My general practice is well managed. It cares about the quality of care I and other patients receive and the safety of patients and staff	GP, ZN, RM, GS
111	My general practice has a website that works and I can use it. If there is a problem with the website the practice staff are quick to notice and fix it.	

Financial competence

My general practice is financially sound

112	My general practice does not stop me receiving the care I need because it costs too much, but they also try and save the NHS money when they can.	GS
113	I am not concerned about the financial security of my general practice	

Individual competence

I have confidence in the standard of care I get from the doctors and nurses

114	I have confidence in the skills and knowledge of my doctor and nurse	MR, AD
115	My doctor and nurse is well trained, up to date, and has a wide range of knowledge and skills	GP, TF, RM
116	If something has gone wrong, my doctor or nurse will try to learn from this so it doesn’t happen again. They will report what has happened and share their learning with other people.	RC, ZN, RM
117	My doctor and nurse tells me when they do not know something	
118	My doctor and nurse are honest when they have gotten something wrong	
119	If my doctor or nurse see something that is going wrong that is outside their control, in my general practice or the NHS, they will tell someone	

	who can do something about it, even if this might be difficult for them personally or professionally	
120	My doctor and nurse provides a thorough physical examination	
121	My doctor and nurse always takes my blood pressure	
122	My doctors and nurses have modern equipment to perform any tests that need to be done	

Management leadership

I have confidence that my general practice is well managed

123	My general practice and all the staff are happy to consider change and working in different ways to support my care and the care of other patients	GP, MK
124	My general practice is small, so when change happens it happens quickly and all the staff know about it	

Transparency

My general practice is open and honest

125	My general practice encourages feedback from me, acts on this feedback, and lets me know what they have done.	RC, RM
126	My general practice actively promote how to give feedback or make a complaint.	
127	My general practice publish the result and report of their CQC inspection and other information which help me to know if it is a good practice and well managed	

Safety

My general practice provide safe care

128	All the staff in my general practice aim to provide care which is safe and doesn't make my health worse	AD, ZN, GS

Appendix 20. Final list of potential features to go into the survey

Access to care		
	Feature	**Potential levels of the feature**
1	How long your appointment lasts	2 minutes shorter than usual
		The same length as usual
		5 minutes longer than usual
		10 minutes longer than usual
2	How many days you wait to get an appointment	Longer than usual
		The same as usual
		Shorter than usual
4	How you can talk to the doctors and nurses	Fewer options than now (face to face only)
		The same options as now (face to face and telephone)
		More options than now (current options and online)
5	When you can have an appointment	Fewer evening, morning, or weekend appointments
		The same times as now
		More evening, morning, or weekend appointments
6	How easy is it to get a home visit	More difficult than usual
		The same as usual
		Easier than usual
7	How easy it is to book an appointment	More difficult than usual
		The same as usual
		Easier than usual

How I am treated during the appointment – person centred care

	Feature	Potential levels of the feature
8	How the doctors and nurses treat you	More neutral and business-like than usual
		No change from usual
		More friendly and personal than usual
9	How well the doctors listen and pay attention to you	Less carefully than usual
		No change from usual
		More carefully than usual
10	How involved you are in making choices about your care	Less involved than usual
		No change from usual
		More involved than usual
11	How many problems you can discuss in your appointment	Only one problem per appointment
		No change from usual
		As many problems as you want
12	How often community groups and lifestyle activities are suggested	Less often than now
		No change from now
		More often than now
14	How you are supported to manage your own health	Less support and less personal advice than usual
		No change from usual
		More support and more personal advice than usual

Continuity of care

	Feature	Potential levels of the feature
15	How well your doctor or nurse knows your medical history	Less well than now No change from now Better than now
16	How well your doctor or nurse knows you as a person	Less well than now No change from now Better than now
17	How often you get your choice of doctor and nurse	Less often than now No change from now More often than now

Co-ordination of care

	Feature	Potential levels of the feature
19	How many services are offered by the practice	Fewer services than now The same services as now More services than now

Equity

	Feature	Potential levels of the feature
20	How much patients are charged for requests for letters of support	More than now No change from now Less than now
21	How interpretation services are provided	No change from now (telephone interpreter) More options than now (face-to-face interpreter)
22	How the practice treats different groups of patients	All patients are treated the same Priority is given to patients with more health problems

Quality of care		
	Feature	**Potential levels of the feature**
23	How the receptionists treat you	More neutral and business-like than usual
		No change from usual
		More friendly and personal than usual
24	How well the practice protects your privacy at reception	No change from now
		Better than now
25	How warm, clean, and tidy the environment is	Worse than now
		The same as now
		Better than now
27	How often you are asked about your experience at the practice	Less often than now
		The same as now
		More often than now
30	How the staff respond to feedback and complaints	Slower to act than usual
		The same as usual
		Quicker to act than usual

Appendix 21. Example of survey with attributes from the pilot

[Practice Logo]

Have your say:

What would you change?

Your patient group and the staff here are thinking about changes we can make to improve the care we give.

We can make changes, but sadly we can’t do everything.
Deciding to change one thing often means we can’t do something else (we make trade-offs).
We would like to know what you would prefer to change.
For example, would you prefer to get an appointment quicker, even if it means you don’t get your choice of doctor as often?

Please could you help us by filling in this survey?

All your answers are confidential and cannot be used to identify you.

Your survey responses will be stored and may be used for future research. By completing the survey you are giving your consent for this to happen. Reception have a leaflet they can give you with detailed information on how your data will be stored.

Thank you!

How to complete the survey

You can complete the survey if you are a patient, or the carer, friend or relative of a patient.

There are no right or wrong answers. Just complete it as best you can.

In each question on the next page, please read all of the options under ‘Set of changes A’ and ‘Set of changes B’.
Then tick whether you would like this practice to make ‘Set of changes A’ or to make ‘Set of changes B’.

You may not like either of them but tick the one you think is better.

Question 1.
Please read the information below.
Please tick whether you would prefer this practice to make ‘Set of changes A’ or ‘Set of changes B’.

	Set of changes A	**Set of changes B**
How the receptionists treat you	More friendly and personal than usual	More neutral and business-like than usual
How the practice treats different patients	Priority is given to patients with extra needs	Priority is given to patients with extra needs
How the doctors listen and respond to you	More carefully than usual	Less carefully than usual
How the staff respond to feedback and complaints	The same as usual	The same as usual
How many services are offered by the practice	Fewer services than now	More services than now
Please tick Set of changes A or B	☐	☐

Question 2.

Please read the information below.

Please tick whether you would prefer this practice to make 'Set of changes A' or 'Set of changes B'.

	Set of changes A	Set of changes B
How the receptionists treat you	More neutral and business-like than usual	More friendly and personal than usual
How the practice treats different patients	Priority is given to patients with extra needs	All patients are treated the same
How the doctors listen and respond to you	No change from usual	No change from usual
How the staff respond to feedback and complaints	Less interested and slower to act than usual	More interested and quicker to act than usual
How many services are offered by the practice	More services than now	Fewer services than now
Please tick Set of changes A or B	☐	☐

Question 3.

Please read the information below.

Please tick whether you would prefer this practice to make 'Set of changes A' or 'Set of changes B'.

	Set of changes A	Set of changes B
How the receptionists treat you	No change from usual	No change from usual
How the practice treats different patients	All patients are treated the same	All patients are treated the same
How the doctors listen and respond to you	Less carefully than usual	More carefully than usual
How the staff respond to feedback and complaints	Less interested and slower to act than usual	More interested and quicker to act than usual
How many services are offered by the practice	More services than now	Fewer services than now
Please tick Set of changes A or B	☐	☐

The choices people make are affected by their experience. Answering the next questions will help us to understand what different people think is most important.

Your answers will not be used to identify you. If you don't want to answer any of them just leave them blank.

Q4. Why did you visit [name of practice] today? (Tick all that apply)

For me ☐ I'm a carer ☐ I'm with a friend/family member ☐

Q5. Who did you visit at [name of practice] today? (Tick all that apply)

A doctor ☐ A nurse ☐ Receptionist ☐ Other ☐ ________

Q6. What sort of appointment did you have today (if any)? (Tick one)

Non Urgent ☐ Urgent ☐ Other ☐ ____________

Q7a. Do you have a long term (lasting longer than 12 months) physical or mental health condition, disability or illness?

Yes ☐ No (go to Q8) ☐ Don't know ☐

Q7b. If you answered 'Yes', does it affect your daily life?

A lot ☐ A little ☐ Not at all ☐

Q8. How many times have you visited [name of practice] in the last 12 months for any reason?

0-3 times ☐ 4-10 times ☐ More than 10 times ☐

Q9. Would you recommend [name of practice] to friends and family?

☐ Extremely likely	☐ Likely	☐ Neither likely or unlikely	☐ Unlikely	☐ Extremely unlikely

Q10. How easy is it for you to attend appointments between 9am-5pm?

Easy ☐ Neither easy or difficult ☐ Difficult ☐

Q11. How old are you? (please write) ____________

Q12. What is your gender? Male ☐ Female ☐ Other ☐

Q13. What level of education have you have completed?

School ☐ Sixth form/College ☐ University Degree ☐

Q14. What is your ethnic group?

White ☐ Mixed ☐ Black ☐ Asian ☐ Other ☐ __________

Is there anything else that you would change in the practice or like to tell us?

The patient group and the staff will discuss the results and plans for change at the next patient group meeting.

The meeting is on [date and time].

If you would like to join us, ask at reception for details or just come on the day.
Everyone is welcome.

The results will be published on the notice board, website, and in our newsletter before [month and year].

Thank you for taking the time to complete this survey.

This survey has been produced by a group of patients and GPs working together at the University of Leeds and is funded by a National Institute for Health Research Doctoral Research Fellowship.

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Appendix 22. Poster for ballot box survey

[Practice Logo]

Have your say: What would you change?

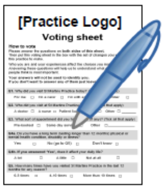
Your patient group and the staff here are thinking about changes we can make to improve the care we give to you.

We can make changes, but sadly we can't do everything.
Deciding to change one thing often means we can't do something else.
We would like to know what you would prefer to change.
For example, would you prefer to get an appointment quicker, even if it means you don't get your choice of doctor as often?

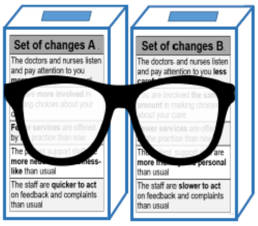
Please could you help us by voting. It only takes 3 minutes

How to vote

You can vote if you are a patient, or the carer, friend or relative of a patient.



1. Fill in the voting sheet. **Your answers will not be used to identify you.**



2. Read all of the options on the front of the boxes 'Set of changes A' and 'Set of changes B'.

3. Put the voting sheet in the box with the set of changes you would prefer this practice to make.

Your responses will be stored and may be used for future research. By voting you are giving your consent for this to happen. Reception have a leaflet they can give you with detailed information on how your data will be stored

What happens next?

The patient group and the staff will discuss the results and plans for change at the next patient group meeting.

The meeting is on [date and time] at [name of practice].

If you would like to join us, ask any member of Reception for details or just come on the day.

Everyone is welcome.

The results will be published on the notice board, newsletter and website before [month and year].

Thank you for voting

Appendix 23. Voting sheet for ballot box survey

[Practice Logo]

Voting sheet

How to vote

Please answer the questions on **both sides of this sheet.**
Then put this voting sheet in the box with the set of changes you would prefer this practice to make.

Who you are and your experiences affect the choices you make.
Answering these questions will help us to understand what different groups of people think is most important.

Your answers will not be used to identify you.
If you don't want to answer any of them just leave them blank.

Q1. Why did you visit [name of practice] today? (Tick all that apply)

For me ☐ I'm a carer ☐ I'm with a friend/family member ☐

Q2. Who did you visit at [name of practice] today? (Tick all that apply)

A doctor ☐ A nurse ☐ Receptionist ☐ Other ☐ ________

Q3. What sort of appointment did you have today (if any)? (Tick all that apply)

Pre-booked ☐ Same day service ☐ Other ☐______________

Q4a. Do you have a long term (lasting longer than 12 months) physical or mental health condition, disability or illness?

Yes ☐ No (go to Q5) ☐ Don't know ☐

Q4b. If you answered 'Yes', does it affect your daily life?

A lot ☐ A little ☐ Not at all ☐

Q5. How many times have you visited [name of practice] in the last 12 months for any reason?

0-3 times ☐ 4-7 times ☐ 8-11 times ☐ 12 or more times ☐

Q6. Would you recommend the [name of practice] to friends and family?

☐ Extremely likely	☐ Likely	☐ Neither likely or unlikely	☐ Unlikely	☐ Extremely unlikely

Q7. How easy is it for you to attend appointments between 8.30am-5pm?

Easy ☐ Neither easy or difficult ☐ Difficult ☐

Q11. How old are you? (please write) ____________

Q9. What is your gender? Male ☒ Female ☐ Other ☐

Q10. What level of education have you have completed?

School ☐ Sixth form/College ☐ University Degree ☐

Q11. What is your ethnic group?

White ☐ Mixed ☐ Black ☐ Asian ☐ Other ☐ __________

Is there anything else that you would change in the practice or tell us?

Now put this sheet in the box with the set of changes you would prefer this practice to make.

Thank you for taking the time to vote!

This voting exercise has been produced by a group of patients and GPs working together at the University of Leeds and is funded by a National Institute for Health Research Doctoral Research Fellowship.

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National Institute for Health Research

Appendix 24. Data protection information for survey

How your answers (data) will be stored

This depends on which version of the survey you have completed.

- **Paper version**. Your general practice will store all the responses securely until the survey is finished. They will then send them to Accent which is an independent market research company. Accent will store this data securely and combine all the answers together into one spreadsheet. This spreadsheet will be sent to Jess Drinkwater who will store it securely at the University of Leeds.
- **Online version.** Your answers will be electronically sent to Accent which is an independent market research company. Accent will store this data securely and combine all the answers together into one spreadsheet. This spreadsheet will be sent to Jess Drinkwater who will store it securely at the University of Leeds.
- **Voting box version.** Your general practice will store all the responses securely until the survey is finished. They will then give them to Jess Drinkwater who will combine all the answers into one spreadsheet and store it securely at the University of Leeds.

The combined data will be stored securely at the University of Leeds for 5 years after the end of the study. During this time it might be used for future research.

For more information Jess Drinkwater can be contacted at the University of Leeds on

Tel: (0113) 343 0868 or email j.m.drinkwater@leeds.ac.uk

University of Leeds and their responsibilities for your data

The University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for five years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at www.leeds.ac.uk/secretariat/data_protection.html

Accent and their responsibilities for your data

Accent is contracted to work with the researchers at the University of Leeds to deliver the paper and online versions of this survey. Accent is an independent market research company and this research is being conducted under the terms of the Market Research Society code of conduct and is completely confidential. If you wish you can find out more about the Market Research Society at https://www.mrs.org.uk/standards/code_of_conduct. If you would like to confirm Accent's credentials please call the Market Research Society free on 0800 975 9596.

Accent is a GDPR compliant organisation, notified with the Information Commissioner for the purpose of processing personal data for research purposes. For more information on how Accent uses personal data, please see our privacy statement at www.accent-mr.com/privacy/. Any personal data collected over the course of this survey will be held securely and will not be shared with any third party unless you give permission (or unless we are legally required to do so)

To get back to the survey, please close this window by clicking the ‘x’ at the top of this page

Appendix 25. Ethical approval for intervention field testing

Dear Jess

Please find formal approval for MREC 18-009 which was approved on 17 Octrober 2018.

MREC 18-009 - Patient Participation in Improving General Practice: Evaluating the intervention
Approval granted 17 October 2018

NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.

I am pleased to inform you that the above research ethics application has been reviewed by the School of Medicine and Health (SOMREC) Committee and on behalf of the Chair, I can confirm a favourable ethical opinion based on the documentation received at date of this email.

Please retain this email as evidence of approval in your study file.

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see https://ris.leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/ or contact the Research Ethics Administrator for further information fmhuniethics@leeds.ac.uk if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes
Kaye Beaumont
On behalf of CHAIR, SOMREC

Appendix 26. Participant information leaflet: Observing meetings

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is doing this research?

We are a co-research group of patients, GPs, general practice staff, and researchers who are interested in making patient involvement in general practice have a real impact. The study is being led by Jessica Drinkwater, as part of a National Institute for Health Research doctoral research fellowship. Jessica is also a GP with an interest in how to support and develop patient involvement in general practice

What is the research about?

One role of patient participation groups (PPGs) is to be involved in improving general practice services. But there is little evidence about how to do this meaningfully. We have designed a process which aims to support patients and general practice staff to work together to improve general practice services for their whole patient population.

The process involves three stages. Firstly, we will work with PPG members and practice staff to identify five areas of your general practice where you would like to see change. Secondly, we will turn these into a survey specifically for your practice and help the PPG to distribute this. The survey will ask the wider patient population about their preference for change from the five areas identified in the first stage. Finally, we will meet with you to discuss the results, help you interpret them, and plan possible changes.

We would like to test this process with 2 PPGs and general practices to answer the following questions:

1. Does the process make sense to PPG members and general practice staff?
2. Is the process something PPG members, practice staff, and other patients want to get involved in?
3. What do PPG members and practice staff have to do to make the process work?
4. Overall what do PPGs and practice staff think of the process?

Why have you been chosen?

We will be working with 2 different PPGs and general practices in Leeds and Manchester. Your PPG and the staff in your general practice have shown an interest in being involved in this study.

What will I be asked to do if I take part?

We will be asking everyone in your PPG and the staff supporting them if they are willing to take part. If you all agree, Jessica Drinkwater and 1 or 2 other members of the research group would like to come and meet you all and explain the research in detail.

Once your PPG has agreed to participate, we would like you to take part in a series of meetings and activities as outlined below. The meetings will be similar to your normal meetings, but will involve structured activities and discussions. The process may involve more meetings than your PPG normally has. The process will go as follows:

1. There will be 2 separate meetings, one with patient PPG members and one with the general practice team. At both meetings we will discuss possible areas for change and group these depending on whether the group is interested in them or not.
2. A couple of weeks later we will hold a further meeting with PPG members and staff together. At this meeting we will ask everyone to vote for their top 5 areas for change. We will then discuss the results and agree the final 5.
3. After this we will develop three versions of the survey. A paper version which can be handed out, an online version, and a version where people vote in a box in the waiting room. We will then attend another meeting to show the PPG members how to help people complete the surveys. We will then expect the PPG and practice to distribute the survey. Jessica Drinkwater will analyse the results of the survey.
4. Once the survey is complete and analysed (usually 1-2 months later) we will hold a further meeting with PPG members and staff together. At this meeting we will explain the results and encourage you to develop a plan for acting on the results.
5. After this we would like to attend the next 2-4 normal PPG meetings to see what happens next. It will be up to the PPG and practice staff what happens in these meetings.

Jessica Drinkwater and one other member of the co-research group would like to attend each meeting and make notes of what happens during them. This will help us understand whether the process works and is useful to your PPG, and if there are improvements we can make. We would also like to look at any documents your group uses in these meetings for example agendas, minutes, and terms of reference. Finally, we would like to interview some of your group members about their experiences of this process (we will explain this in more detail if you are willing to take part).

We think that the first 4 steps (detailed above) will take approximately 4 months. The final part of the process (step 5) will depend on how often your PPG usually meets. The study will not last longer than one year. For more detail about the timeline please see flowchart of activities at the bottom of this form.

What happens to the data and how is confidentiality maintained?

All information collected during this study will be kept confidential. Notes from the meetings and meeting documents will be anonymised so that any personal information (such as names, addresses, or places of work) will not be included in the research.

Anonymous notes from the meetings and meeting documents will be password protected and shared with the co-research group who are helping with the research. We will discuss these notes and documents to help us decide whether the process works in the 2 practices. To help us understand and interpret this research data further, Jessica Drinkwater will discuss it with her academic supervisors at the Leeds Institute of Health Sciences, University of Limerick and University of Hull. Sections of the anonymous notes may also be presented in reports, presentations, and scientific publications. We will send you a summary of the results at the end of the study.

During the study all the research data will be stored in a locked filing cabinet or in password protected computer files at the University of Leeds. The secure research data will be kept for 5 years after the study has ended. After the study has ended the anonymised data will be stored long term in the University of Leeds Research Data Repository. This anonymised data may be used to shape relevant future work by authorised researchers.

All information will be kept confidential unless there is evidence of actual or intended harm to others, for example criminal activity or patient-safety issues, although these are very unlikely to arise. In addition, in the unlikely event of concerns about quality of care being raised, under Jessica Drinkwater's professional code of conduct she will have to report the matter.

The University of Leeds is the sponsor for this study based in the United Kingdom. They will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for five years after the study has finished.

You cannot access, change or move your information, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at www.leeds.ac.uk/secretariat/data_protection.html

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to participate you can keep this information sheet, and will be asked to sign a consent form. Even after you have agreed to take part you can still withdraw at any time without giving a reason and with no consequences. If you withdraw after participating in a meeting the fact you attended will be on record and so this will still be used anonymously. If you do not wish to take part, or decide at a later date you no longer wish to take part, I will not observe you further. If you still take part in PPG meetings this means the project will have to stop. There will be no detrimental effects to your group. If the rest of the group want1 to continue with the research, we will discuss this with you and them and try to find a solution that everyone is happy with where you do not have to take part. If we cannot find a solution the project will stop.

What are the benefits and risks of participating in the research?

There are no immediate benefits or risks to taking part in this study. However, we hope that the process we have designed will help your PPG and practice to work together and may improve services at your practice. Data collected about this may help other PPGs and general practices to work together.

We understand that some people feel under ‘scrutiny’ when they are being observed. This study is not about making a judgment about how good or bad your group is, we are just trying to discover what happens during the process. Please talk to Jessica Drinkwater or another member of the co-research group if you feel uncomfortable.

Will I be paid for participating in the research?

You will not be paid individually for taking part in the research, although we will be very grateful. However, your general practice will be paid a one off fee of £750 to compensate them for any extra work or resources that they might have to use to help with the survey or having to put on extra meetings.

Who has given permission for the research?

This research has been approved by the University of Leeds School of Medicine Research Ethics Committee (SoMREC project number 18-009).

What if there is a problem?

If you are worried about the research or have any questions please speak to Jessica Drinkwater, a member of staff, or the chair of your PPG. Alternatively you can contact Jessica Drinkwater’s academic supervisor Professor Robbie Foy.

Jessica Drinkwater	Academic Supervisor:
Researcher and GP	Professor Robbie Foy
Tel: (0113) 343 0868	Tel: (0113) 343 4879
Email: j.m.drinkwater@leeds.ac.uk	Email: r.foy@leeds.ac.uk

Thank you very much for taking time to read this information sheet.

Appendix 27. Consent form: Observing meetings

Researcher: Jessica Drinkwater

If you are happy to participate please complete and sign the consent form below

	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet version 2 dated 20/9/2019 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. However, if I withdraw after having been observed in a meeting, any data that has already been provided will still be used in the study.	
I agree to being observed during PPG meetings and prioritisation survey training and notes being made during the meetings. If I no longer wish to be observed I will inform a member of the research team or my general practice.	
I agree that notes about meetings, meeting documents, and this consent form can be stored securely on University of Leeds computers for 5 years after the study has ended.	
I understand that relevant sections of the data collected during the study may be looked at by individuals from regulatory authorities at the University of Leeds.	
I understand that my responses will be kept strictly confidential by the co-research team. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I agree to the use of anonymous excerpts of notes from the meetings in study reports.	
I give permission for members of the co-research team and supervisory team to have access to anonymised notes of meetings and meeting documents.	
I agree for the data collected from me to be stored and shared for use in relevant future research in an anonymised form.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change during the study period.	

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 28. Participant information leaflet: Interviews

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is doing this research?

We are a co-research group of patients, GPs, general practice staff, and researchers who are interested in making patient involvement in general practice have a real impact. The study is being led by Jessica Drinkwater, as part of a National Institute for Health Research doctoral research fellowship. Jessica is also a GP with an interest in how to support and develop patient involvement in general practice.

What is the research about?

One role of patient participation groups (PPGs) is to be involved in improving general practice services. But there is little evidence about how to do this meaningfully. We have designed a process which aims to support patients and general practice staff to work together to improve general practice services for their whole patient population.

Your PPG has been taking part in this process and allowing us to observe meetings to see what happens. We would now like to interview some of you about this process to help us answer the following questions:

1. Does the process make sense to PPG members and general practice staff?
2. Is the process something PPG members, practice staff, and other patients want to get involved in?
3. What do PPG members and practice staff have to do to make the process work?
4. Overall what do PPGs and practice staff think of the process?

Why have you been chosen?

As you know, we have been observing your PPG going through the above process. We are now interested in interviewing both patients and staff to get your feedback on it. You have been invited to take part in an interview because you have played a key role in the process. We would like to interview patient PPG members and members of staff. We will also be interviewing patients and staff in one other practice we have been working with in Leeds and Manchester.

What will I be asked to do if I take part?

We would like to interview you to find out what you think about the process and if you think it has changed the way the PPG and the practice work together. The interview will be conducted by Jessica Drinkwater or another member of the co-research team by telephone or video. The interview will be audio-recorded using an encrypted digital recorder. The length of the interview will vary, depending on how much you wish to talk about and how much time you can spare. It is likely to last about 30-60 minutes.

What happens to the data and how is confidentiality maintained?

All information collected during this study will be kept confidential. As soon as possible after the interview has finished, the encrypted recording will be emailed to Jessica Drinkwater who will upload it onto the University of Leeds One Drive which is password protected. The audio recording will then be deleted from the digital recorder.

The encrypted audio-recording of the interview will be emailed to a transcriber who will transcribed and anonymise it so that any personal information (such as names, addresses, or places of work) are deleted. The transcript of the interview will be password protected and shared with the co-research group who are helping with the research. We will discuss the interview transcripts to help us decide whether the process works in the 2 practices. To help us understand and interpret this research data further, Jessica Drinkwater will discuss it with her academic supervisors at the Leeds Institute of Health Sciences, University of Limerick and University of Hull. Anonymous excerpts of interview transcripts may also be presented in reports, presentations, and scientific publications. We will send you a summary of the results at the end of the study.

During the study all the research data will be stored in a locked filing cabinet or in password protected computer files at the University of Leeds. The secure research data will be kept for 5 years after the study has ended. After the study has ended the anonymised transcripts will be stored long term in the University of Leeds Research Data Repository. These transcripts may be used to shape relevant future work by authorised researchers.

All information will be kept confidential unless there is evidence of actual or intended harm to others, for example criminal activity or patient-safety issues, although these are very unlikely to arise. In addition, in the unlikely event of concerns about quality of care being raised, under Jessica Drinkwater's professional code of conduct she will have to report the matter.

The University of Leeds is the sponsor for this study based in the United Kingdom. They will act as the data controller for this study. This means that they are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for five years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at: www.leeds.ac.uk/secretariat/data_protection.html

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you can keep this information sheet, and be asked to sign a consent form.

If you take part in an interview you can withdraw without giving a reason up to 1 week after the interview, and any data already provided will be deleted. However after 1 week, data analysis will have begun and it will not be possible to delete your data.

What are the benefits and risks of participating in the research?

There are no immediate benefits or risks to taking part in this study. However, we hope that the process we have designed will help your PPG and practice to work together and may improve services at your practice. Your views on whether the process is useful will help to shape the process and how other practices use it. This may help other PPGs and general practices to work together.

Will I be paid for participating in the research?

You will not be paid for taking part in the research, although we will be very grateful.

Who has given permission for the research?

This research has been approved by the University of Leeds School of Medicine Research Ethics Committee (SoMREC project number 18-009).

What if there is a problem?

If you are worried about the research or have any questions please speak to Jessica Drinkwater, a member of staff, or the chair of your PPG. Alternatively you can contact Jessica Drinkwater's academic supervisor Professor Robbie Foy.

Jessica Drinkwater

Researcher and GP

Tel: (0113) 343 0868

Email: j.m.drinkwater@leeds.ac.uk

Academic Supervisor for fellowship:

Professor Robbie Foy

Tel: (0113) 343 4879

Email: r.foy@leeds.ac.uk

Thank you very much for taking time to read this information sheet.

Appendix 29. Consent form: Interviews

Researcher name: [enter name of research who is conducting the interview]

If you are happy to participate please complete and sign the consent form below

	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet version 4 dated 24/03/2020 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw up to 1 week after the interview without giving any reason and without there being any negative consequences. Any data already collected will be deleted. After 1 week it will not be possible to delete the data collected.	
I agree that the interview can be audio-recorded.	
I agree transcriptions of my interviews and this consent form can be stored securely on University of Leeds computers for 5 years after the study has ended.	
I understand that relevant sections of the data collected during the study may be looked at by individuals from regulatory authorities at the University of Leeds.	
I understand that my responses will be kept strictly confidential. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I agree to the use of anonymous quotes in study reports.	
I give permission for members of the co-research team and supervisory team to have access to my anonymised transcripts.	
I agree for the data collected from me to be stored and shared for use in relevant future research in an anonymised form.	
I agree to take part in the above research project	
I agree to take part in a telephone or video interview	

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix 30. Results of prioritisation survey – Practice 1

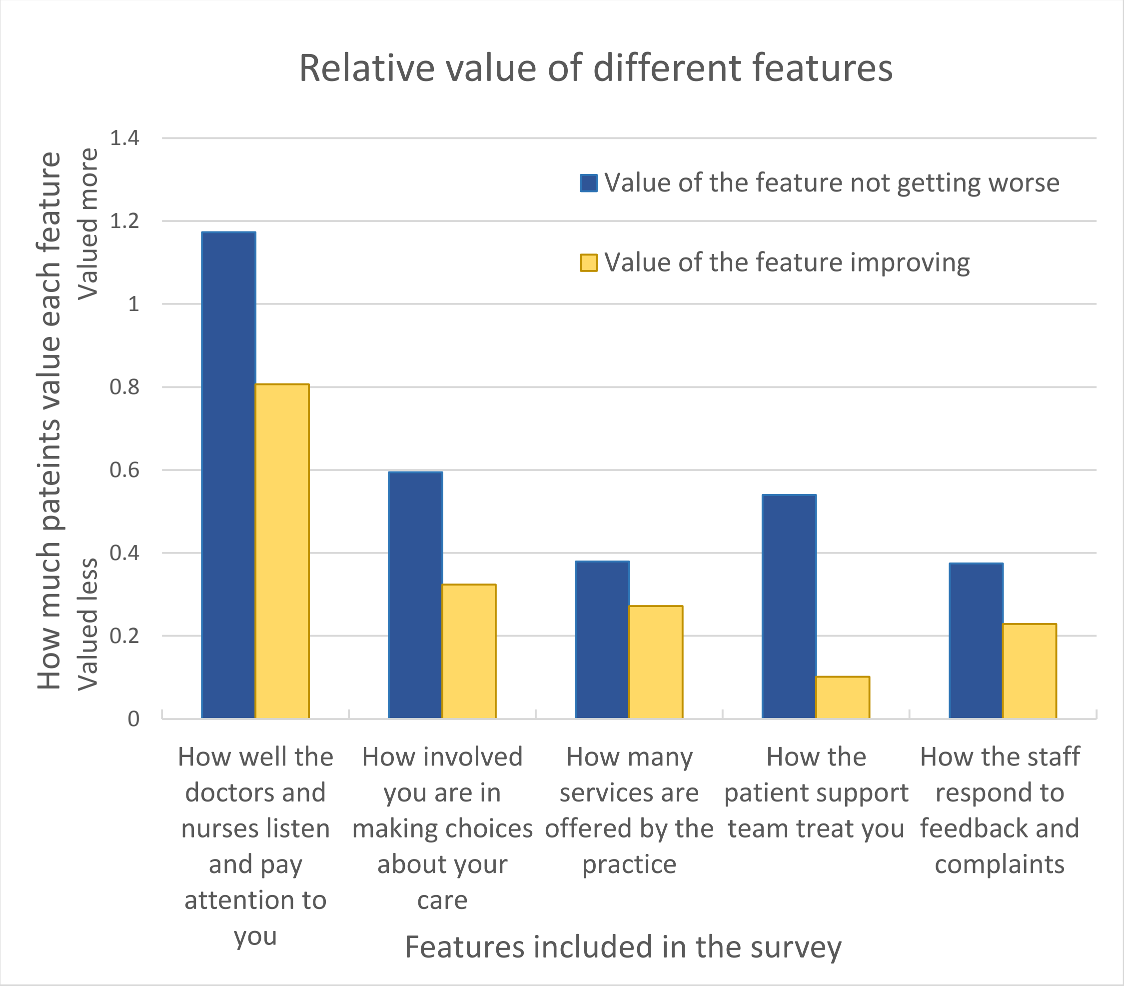
[Practice 1 logo]

Prioritisation survey results

Who took part?

- 333 people completed the survey.
  - 160 people completed it online after getting a text message from the practice.
  - 115 people completed a paper version handed out in the waiting room.
  - 58 people voted in a ballot box in the waiting room.
- 52 was the average age of people who completed the survey. The oldest person was 91 and the youngest was 10.
- More women (66%) than men (44%) completed the survey.
- Most people were White (63%), Black (17%) or Asian (12%).
- Most people had a University degree (60%).
- Just over half (58%) of the people had a long term condition.
- Most people were either extremely likely (40%) or likely (41%) to recommend [name of Practice 1] to friends and family.
- People who completed the paper version of the survey were younger, less educated, and less likely to be White, than people who completed the survey online or by voting.

What features did the population of [name of Practice 1] value?



Main result

- The feature patients at [name of Practice 1] value most is "How well the doctors and nurses listen and pay attention to you".
- Patients value this feature not getting worse, and improving, more than they value any other feature. This feature is really important to patients.
- The second feature patients value is "How involved you are in making choices about your care".

From the graph you can see that the blue sections are all bigger than the yellow sections. This shows that generally people value things not getting worse, more than they value improvements.

Other results

- Patients who have good experience of the practice are more likely to value features not getting worse, rather than improvements.
- Patients who do not recommend the practice are more likely to value improvements, rather than features not getting worse.
- Black and minority ethnic patients valued features differently to White patients. This may be because they rate their experience lower.
- Patients with long term conditions valued features differently to those without long term conditions.

Free text comments

159 of the 333 people who completed the survey made free text comments.
There were positive and negative comments.
Comments were about the different features in the survey (see graph), but also about the following things:

- Appointments out of hours
- Waiting time for an appointment
- Being able to see the same GP
- Longer appointments
- Difficult appointment system
- Not getting through on the phone
- Type of appointments (online, email)
- Late running clinics
- Administration issues
- Patient centred practice
- Car parking
- Waiting room issues
- More male GPs
- Patient group issues

Appendix 31. Results of prioritisation survey – Practice 2

[Practice 2 logo]

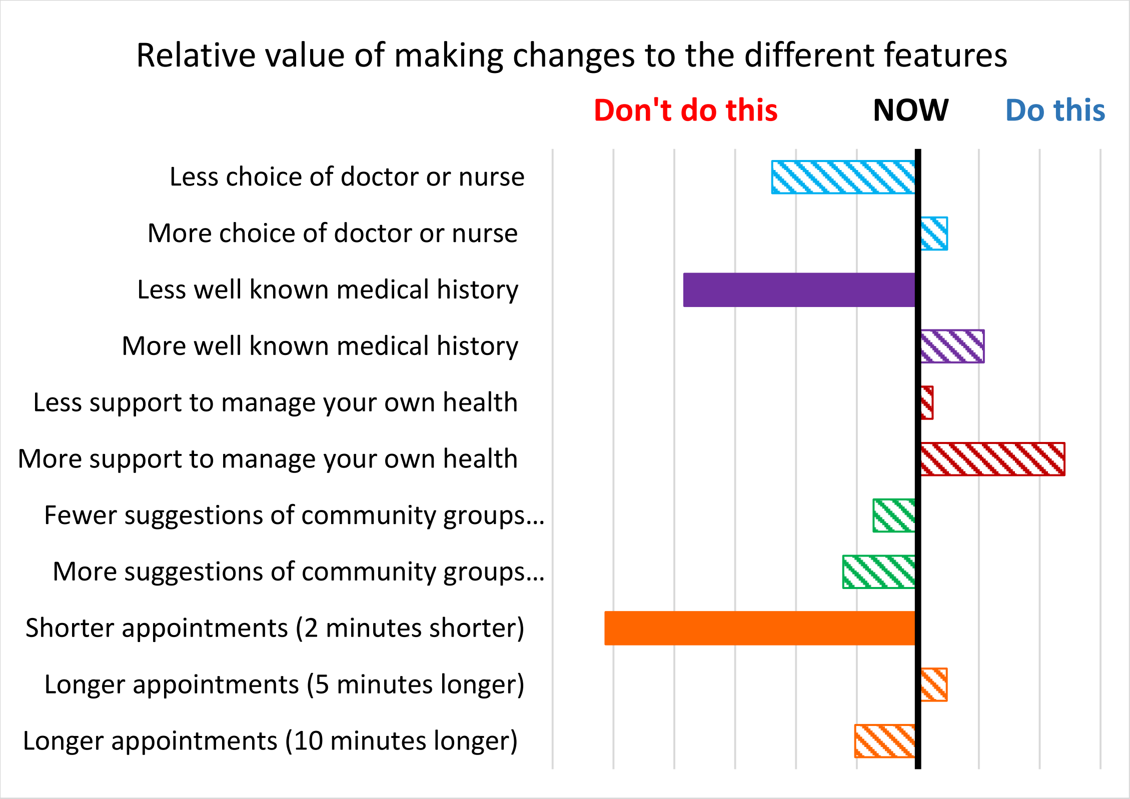
Prioritisation survey results

Who took part?

- 343 people completed the survey. There are 7,815 patients at the practice.
    - 153 people completed it online after getting a text message from the practice.
    - 116 people completed a paper version handed out in the waiting room.
    - 74 people voted in a ballot box in the waiting room.
- The average age of people who completed the survey was 46. The oldest person was 87 and the youngest was 11.
- More women (69%) than men (31%) completed the survey.
- Most people who completed the survey were White (51%), Black (22%) or Asian (14%).
- Just over half the people had a University degree (51%).
- Half (50%) of the people had a long term condition.
- Most people were either extremely likely (26%) or likely (36%) to recommend the [name of Practice 2] to friends and family.
- People who completed the paper version of the survey appeared more diverse than people who completed the survey online or by voting.

What features did the population of the [name of Practice 2] value?

The results show what patients would prefer the practice to do more of and what they don't want to see get worse if changes are made.



■ Solid coloured bars indicate a clear result.

▨ Stripey coloured bars indicate a trend rather than a clear result

Main result

- Patients at the [name of Practice 2] do not want shorter appointments.
- There is a trend for patients wanting appointments to be 5 minutes longer, but they do not want appointments to be 10 minutes longer.
- Patients do not want their doctor or nurse to know their medical history less well than now.
- There is a trend for patients wanting their doctor or nurse to know their history better.
- This is consistent with written free text comments (see below).

Other results

- There is a trend that patients would like more support to manage their own health. This is particularly true for patients with no long term conditions.
- Patients do not really have a preference about having less support to manage their own health.
- There is a trend that patients do not want less choice of doctor or nurse than now, and a smaller trend that they would prefer more choice of doctor or nurse. This is also consistent with the free text comments.
- Patients did not have a strong preference for the feature “how often community groups and lifestyle activities are suggested”.

Overall there is quite a lot of variation in what different individual people value and that is why many of the results are trends and not clear cut.

Free text comments

179 of the 343 people who completed the survey made free text comments.
There were positive and negative comments.
Some comments were about the different features in the survey (see graph). But the majority of comments were about other issues, especially the appointment system and reception team:

- Getting through on the telephone
- Booking an appointment
- Waiting time for an appointment
- Out of hours appointments
- Alternatives to face to face appointments
- Online services
- Privacy at reception
- Receptionists
- Doctors and nurses
- Clinics running late
- Administration
- Waiting room and building issues
- Services offered by the practice
- Patient safety
- Practice accessibility
- Patient group issues

I am happy to provide a longer version of the free text comments with quotes arranged under each of the above themes.

One person offered their services as a DJ including their contact details.

Appendix 32. Action planning sticky note suggestions - Practice 1

Theme	What was written on the sticky note
Distributing the results	“simplify the presentation and put them up in reception”
Share results with Patient Support Team	“share survey results w/pt support team & get them to come up with an action plan”
Communicating with patient population	“More frequent communication with patients – TV screen, newsletter, blog, social media – more detailed + more information + more context.”
Services – more/increased awareness	“Practice needs to advertise services that they offer more”
	“More services – Listed services – How to identify services – Assess demand x cost – Impact assessment – Payment”
	“If more services, what? Further work to get more detail…. (did those who wanted more services fill in comments?)”
	“more clarity about MH assessments”
Reception issues	“work on reception/waiting room issues *confidentiality*”
Car parking	“try to allow more time for people dropping off frail patients. How actively is the waiting time monitored”
Ethnicity and patient experience	“more concentration on the needs of ethnic minorities”
	“seems that ethnic minorities feel left out”
	“Follow up work with those stating negative experiences to understand why”
Being listened to	“Work on people feeling listened to ENOUGH”
	“Communication”
	“Communication skills training (including around compassion)”
Seeing the same GP	“It would be an advantage to see the same GP”
	“See the same GP”
	“Named doctor”
Longer appointments	“consider longer apt times”
	“Longer apt times so longer listening time”
	“Longer appointment sessions”
Waiting times for appointments	“Shorter waiting time for appointments”
	“10 days for an appointment is a long time. Could be improved!”
Increase funding	“try to increase funding for primary care”

Appendix 33. Action planning sticky note suggestions - Practice 2

Theme	What was written on the sticky note
Making the patient group more accessible	“who and at what time attends the patient and staff group – meetings to be reviewed”
Supporting patients to manage their own health	“managing own health.”
	“community health – needs to be informed on board”
	“make it more apparent what self-help groups or social community groups are available in the area”
	“health professionals to discuss ‘managing your own health’ with all the long term patients at a review appointment”
Group consultations	“Group consultations”
Improving the appointment system	“Variation of apt times 10/15 mins.”
	“Appointments – waiting time is crucial”
	“telephone consultations”
	“Triage system between 7-8/8-9
	“e/Skype consultations”
Raising patient awareness about how the appointment system works	“Advertising/dissemination & informing patients of online support needs to be DONE”
	“more marketing/advertising of online services – ie booking appointments – improve website”
	“Make patients aware of alternative booking/appointment opportunities – online/hub etc”
Improving the reception area	“Privacy”
Receptionist training	“Appointments online – receptionists need training”
	“increase customer service from reception staff”