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

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.<br>Understanding of the space developed over time, especially after developing a partnership agreement.<br>Taking on roles within the space deepened understanding of how we wanted to work together. | The space was defined by the fellowship.<br>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.<br>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.<br>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.<br>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.<br>The CRG was not representative of the wider patient population.<br>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”.<br>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.<br>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.<br>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