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Part of the team: Effecting change and sharing power in healthcare settings

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Abstract

In 2019, we, as a group of patients and researchers, were invited to rethink how the executive board received and responded to patient stories at a specific NHS hospital trust in the UK. Through an iterative series of meetings, we were able to co-identify common concerns and together develop a distinctive narrative framework for effecting change by sharing patient experiences. This narrative framework is designed to help patients position themselves as ‘part of their healthcare team,’ emphasising roles and responsibilities between patients and health practitioners to compare ideals with reality in patient experiences. While the project was promising, several factors led the hospital to withdraw from working with the group—including the COVID-19 pandemic and changes in key NHS staff. In this article, we report on key support structures and obstacles which influenced the project, as well as its outcomes and limitations, with a view to constructively informing future endeavours at other healthcare institutions. We offer concluding reflections on the significance of collective voice, accessibility, administrative support, and senior staff buy-in. We feel these reflections are especially important since the cumulative effects of austerity and the COVID-19 pandemic have made meaningful commitment to patient involvement significantly more challenging for healthcare institutions, both in the UK and beyond.

Keywords

PPI, PPIE, healthcare, engagement, feedback, patient experiences, COVID-19, power, framework

Introduction

The NHS constitution¹ for England states that

You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.

For democratic rights to make a meaningful impact, corresponding duties and responsibilities must protect and enable their functions;² *access* to involvement in health care planning is fundamental to its meaningful delivery. Patient engagement and involvement are integral to ensuring that this right is *practically* accessible to health service users who most need to exercise it.^{3,4} While NHS policy has long pushed for greater public involvement in both health practice and research,⁵ it is not clear that the enactment of this involvement is always inclusive. For instance, INVOLVE—a national advisory group aimed at supporting NHS public involvement—raised concerns in 2012 that “those being involved tended to come from a relatively narrow section of the population,”⁶ who are typically “people who are used to being involved, with an

existing connection with the organisation, who are able to volunteer their time and energy, and who understand how organisations, such as research institutes, work.”⁷ In other words, as Beresford et al.⁸ put it, “[t]he experiences of the most exposed, marginalised, and discriminated [...] rarely directly influence the policies and practices that are ostensibly created for their protection.”^{9,10}

The contemporary NHS context is hardly conducive to accessible and ambitious patient involvement and engagement. Resources in health service provision are under pressure, which can foster a system that produces tensions between “individual patient/citizen involvement and collective representation.”¹¹ At a time when service-users and staff are facing multiple challenges at national and international levels,^{12,13,14,15} understanding how to meaningfully engage those who most need access to healthcare is paramount.¹⁶ The COVID-19 pandemic has only served to further strain this system^{17,18} profoundly affecting the psychological health of frontline medical professionals.^{19,20} In our experience and, we suspect, that of many others, it has been difficult to sustain patient engagement initiatives through these trying times.²¹

Precisely because of these obstacles to patient involvement and engagement, and in spite of the challenges they pose to any such process,²² we want to reflect on sustainable

ways that patient experiences can be heard and valued.²³ Rather than replicating processes that are inaccessible to those who most need healthcare processes to work for them, we want to contribute to a “more effective, equitable, and collaborative ‘new normal’” through patient involvement and engagement.^{8,24,25} In this paper, we share what we learnt from our patient-led initiative to show how structural and institutional factors might similarly present support and obstacles for future endeavours. One key outcome has been the development of a narrative lens—being ‘part of the team’—to enable patients to make connections across their individual experiences to effect change. We ultimately argue that institutional commitment is crucial to creating the conditions for meaningful feedback mechanisms in healthcare settings, and that this involves sharing power with patients so that they really are part of the team.

How we met

We are a group of people—service-users/patients, researchers, and healthcare professionals—who came together to explore how patients might meaningfully decide how patient stories are shared with senior management at our local NHS trust. The original impetus of the group was somewhat serendipitous; developments snowballed as various meetings and priorities began to align. Rachel Purtell—an experienced researcher and local NHS service-user—gave a presentation at a local University about a poorly designed National Inpatient Survey that had had no patient involvement in its development. She went on to link the importance of patient and service-user involvement together with engagement in research. A senior member of university staff was in attendance, who happened to also have a role in the local NHS trust. She then invited Rachel to speak at the trust’s Patient Experience Committee, who were grappling with the Care Quality Commission (CQC)’s requirement that the hospital board should solicit and listen to patient stories. While the board was generally aware of issues patients were facing, they wanted a way to ‘humanise’ the facts with which they were being presented.

Rachel’s view was that it is rarely difficult to get patients to talk about their experiences, but for those experiences to have meaningful influence, it would be better to focus on the power dynamics relating to how the experiences were selected to go to the board and who decides what is heard. She importantly asked why patients were not able to choose for themselves which stories got heard by the hospital board—ones that they, as patients, felt best reflected and amplified their experiences to potentially effect change. Aware that the “handpicking of just one or two ‘appropriate’ or ‘acquiescent’ patient representatives to be involved in committees or projects” can reinforce class-based, race-based, and other healthcare inequalities,^{26,6} Rachel suggested that the trust could facilitate a

meaningful sharing of power by taking a new approach. Simply telling individual stories is rarely enough to fix common problems, but perhaps there was scope here for organising something a bit more collectively engaged. In Rachel’s experience, good involvement only *starts* with sharing experience, and then, crucially, it must include decisions taken together on what to do about issues raised through problem solving. Rachel was asked what ‘structure’ would be required to do this, and her reply was that any ‘imposed’ structure from the beginning might inadvertently close down aspects of involvement and that the structure should be emergent as far as possible.

Two initial meetings brought a handful of patients together to discuss this idea, where many of us met for the first time. Group members were invited to share their stories, to begin thinking about commonalities across their experiences, and to accordingly explore a different way to frame feedback to the board. These patients were invited through informal connections and relationships with staff, many of whom had indeed already engaged with patient experience projects or feedback processes in the past. Nevertheless, initial group members had a spectrum of experiences from across the hospital, with a range of ages and backgrounds in attendance—enough, at least, to begin exploring how patients might share and choose stories together and get the idea off the ground.

Jessie Stanier, a PhD researcher based at a local university, was invited by Rachel to join in and document this process so that it could be shared for future learning at the trust and other health organisations. All members of the group agreed to this light-touch mapping of the process, which did not entail the collection of any personal data but instead involved all members of the group as co-authors. (Active group members were offered the opportunity to feedback on this article, as well as the option of being listed as a co-author or included in the acknowledgements.) Rachel facilitated the group meetings as a fellow patient with a background in engaged health research, Jessie took careful notes on the key ideas arising from the group, and Dave Thomas supported the group as a senior staff member with access to administrative resources. While these people provided a minimal structure, making it possible for the group to meet, the content of the discussion grew organically out of group members listening and reflecting on each other’s experiences.

What we did

These first meetings were aimed primarily at listening to any experiences of the hospital that patients wanted to share and to understand in what context patients would feel confident or invested in sharing these with the hospital to effect change. It was clear that the communication by staff to patients about the purpose of

meetings was a little confused. Patients came to the meetings with the expectation that Rachel and Jessie would listen, take their stories, and then decide what to do without them. Whether this was accidental, the upshot of our potentially ambiguous word-of-mouth invitations, or reflective of a slightly default view that ‘patients tell their stories and someone else decides what to do,’ this was almost the complete opposite of our intention. However, once we were able to explain better in-person, it became easier for everyone.

Group members had a few different perspectives on the wording they preferred to use when reflecting on their time as patients. Some said they tended to speak of their ‘experiences’ rather than their ‘stories’, feeling that the latter implied a simplistic or fictional narrative. However, others felt that the word ‘experience’ was more often used to describe events that stand out—usually negative experiences—rather than the continuous and more neutral background of care as a string of events. One person reflected on the pointedness of asking for someone’s past ‘experience’ (of illness), which tended to remind them of bad experiences, and preferred to be asked open questions relating to the present (i.e., ‘how are you doing?’)—particularly by medical practitioners. There were mixed feelings about the word ‘journey’; some explained that this wording felt less relevant if spending more time out of hospital, but others thought that it might help encapsulate the ‘ups and downs’ of healthcare. One person noted that their word choice depended on the bits they were choosing to share with a particular person at a particular time. We have used both the words “story” and “experience” here, though we recognise that individual patients will feel differently about wording, depending on preferences and circumstances.

Many of the issues raised by group members were predictable and are likely to be commonplace across most NHS trusts, such as the impact of waiting times, noise on the ward, issues with parking, and feeling dismissed by staff members. This was expected; the important intervention to be made concerned how the group would deal with these issues raised. As with most involvement, it can be emotionally taxing to repeatedly recount the details of healthcare experiences and dispiriting to encounter the same problems after reporting feedback. It is incredibly important that those seeking and/or facilitating the involvement are not overly driven by agendas and purpose but gently guide to the aim. Facilitators have a responsibility to patients to ensure they are not endlessly asked to repeat experiences. The group agreed that sharing an experience, as a patient, is worthwhile *if there is something to be learnt and if we can trust that sharing the experience will make a difference in the end.*²⁷ This might include changing others’ assumptions or perceptions about our experiences.

Sometimes we might feel proud of what we have come through. Sometimes it might be surprising to others that we found certain aspects of the experience difficult, and there are often examples of both positive and negative instances of care as part of a single patient experience. Sharing an experience through narrative gives us the chance to communicate this complexity. In all cases, however, we felt that minimal conditions of trust, listening, and a degree of agency or power were key to making the sharing of an experience worthwhile. In fact, it became clear that these conditions were a prerequisite for individuals to consider giving individual feedback at all, let alone contributing to any collective endeavour. Several group members were, understandably, sceptical at first. The process of narrating an experience is by no means intrinsically therapeutic and not all people are inclined to experience their lives as enmeshed in narratives.²⁸ In this instance, the positive potential of being able to articulate experiences to effect change needed to be balanced by sufficient trust and evidence of efficacy.

Group members were unclear on the current trust procedure for feedback, so the Interim Chief Nurse, Dave Thomas, was invited along to clarify this process at the next meeting. This opened up a space to further discuss how there are both positive and negative aspects to hospital experiences. Some members of the group were able to reflect on times when established trust, joint decision-making, and continuity of communication meant they felt respected.²⁹ These were sometimes occasions when our perspectives as patients have effected meaningful change for others—particularly other patients but also for staff members. For example, one group member had recommended noise-cancelling headphones to other inpatients to help them get enough peace to rest on the ward. Other group members recounted buzzing for nurses on other patients’ behalf. Others still had sought to make a difference outside of the NHS, through charity work.

The emergent message from the group was that patients are (obviously) essential to the success of their own health care. From this premise, the notion that patients are *part of their health care team* seemed logical. This idea seemed to resonate with all group members—patients and healthcare professionals alike. Rachel and Jessie had been reflecting on notes from the group discussions after each meeting and decided to dedicate the next meeting to addressing some of issues raised through the narrative framework of being ‘part of the team.’ This meeting gave space to see what patients thought about the idea, and whether they felt this might be used to change the feedback process to the board. This narrative lens developed into one of the main outcomes from the initiative, with potential application beyond this specific context.

Part of the team

We understand the ‘part of the team’ framework as pertaining to narrative, in the sense that it serves as a prompt for patients to articulate their experiences with respect to particular priorities and motivations.³⁰ This narration is accordingly underpinned by concern for both the past and the future—not merely an episodic experience—as well as concern for other people in healthcare. Since we were looking to document the process, our reflections have therefore been loosely grounded in narrative inquiry as a methodology, understood as follows:

“[N]arrative inquiry is a way of understanding experience. It is a collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus. An inquirer enters this matrix in the midst and progresses in this same spirit, concluding the inquiry still in the midst of living and telling, reliving and retelling, the stories of the experiences that make up people’s lives, both individual and collective.”³¹

Rather than a straightforward dichotomy between researchers and participants here, however, group members have taken on various roles in shaping the research as co-authors—narrating experiences and reflecting on their significance in the context of the project.

By using a framework to explain a hospital experience in terms of ‘your role’ (i.e., the health care practitioner) and ‘my role’ (i.e., the patient) as ‘part of the team,’ the narrative about the process of care quite radically changes. It is useful to remember that a frame can be defined as “[a] supporting structure of which the outline or skeleton is not filled in; a framework.”³² On this definition, our narrative framework of being ‘part of the team’ leaves the content open to the narrator, as a patient, who no longer takes on an entirely passive role—even when their role might simply be to accept treatment. The narrator is also able to use this framework to identify where members of their healthcare team might have acted otherwise or made the narrator feel especially valued. The framework therefore offers both descriptive and evaluative opportunities and does not separate these two lenses; it is not the case that the patient describes their experience and then the hospital board evaluates what happened, but instead the patient is able to participate on both accounts. These were some examples of evaluation from our documentation, which emerged *after* narrating specific examples of experiences as patients:

“Your role is ensuring I know who the staff are that have a key role in my care, a consultant and/or practitioner and nurses, etc. My role is to explain any concerns or ask questions so that any anxiety does not

affect my clinical outcomes. We are the team that makes decisions about my care together.

I am not ‘difficult’ if I ask questions or know about the problems I have, e.g., the side effects of drugs. My role is to tell you; your role is to listen and understand, refer on where needed, and we make decisions together.

Your role is to explain any change in aspects of my care, e.g., if you need to move me in the middle of the night, you need to explain why and understand that being moved can be distressing/difficult. My role is to understand that this might be necessary and that other patients need to be in the space I was in.”³³

While this framework might be interpreted as somewhat transactional, the assertion of roles on the part of the patient allows them to assume a position of power and situate their voice among those of the health care practitioners with regard to decision-making over their treatment. The idea is obvious, simple, and yet radical, as it immediately shares power in the healthcare relationship; it only requires a different way of thinking about and framing people’s roles. Indeed, during the process of soliciting feedback on this article, one contributor drew a comparison between the phrase ‘part of the team’ and the phrase ‘nothing about it without us’ (used often in the context of disability activism). While this was not originally discussed as part of the group conversations, it is worth considering how the ‘part of the team’ framework might capture some additional nuance in this particular context. Emergency health care situations sometimes *do* call for health practitioners to make decisions without their patients—and that this is justifiably part of the practitioners’ role in the team. However, just because it is not always possible or relevant for patients to have a say in all decisions relating to their care, this does not undermine their role, as part of the team, in non-emergency decision-making.

The idea of sharing experiences through the ‘part of the team’ framework was so thoroughly embraced in our small group that Dave Thomas immediately started to use it in staff training. He found that utilising the stories with registrants in training was of enormous use. Where videos had been recorded, these were direct and at the right length for students to be able to engage with the storytelling in detail. The impact of unfiltered reviews and stories helped students and registered nurses on leadership courses to better understand the views of trust service-users. Trainees found this view particularly useful and, when used in the context of communication education, the narrative framework of being ‘part of the team’ conveyed the voice of the patient powerfully to healthcare professionals—underscoring the importance of the patient-practitioner relationship. The upshot of this direct application was that student nurses better understood the

impact of hearing the voice of the patient in designing both pathways and models of care.

While telling one's story is often felt to be therapeutic in itself,^{34,35} this is rarely enough to challenge power dynamics within medical institutions between medical practitioners and patients.³⁶ While other listening frameworks have been used in similar engagement initiatives—such as the Sweeney Programme,³⁷ Schwartz Rounds,^{38,39} Goldfish Bowl (Involve n.d.),⁴⁰ or Most Significant Change framework (Davies and Dart 2005; NHS England n.d.)^{41,42}—it is of particular importance that the 'part of the team' framework emerged through a process of working with and listening to patients. There is potential for this framework to be used in parallel or conjunction with other frameworks. It therefore has a genuinely distinctive angle, allowing patients both to speak on their own terms *and* feel that their story might make a difference. However, the framework does more than this. The process of listening to others makes it possible for group members to explore for themselves how their stories might have an impact, change power dynamics, and bring patients together in a system that tends to silo and individualise its users.^{6,8,9,26}

The group began to nominate members to share their personal experience with the hospital board through the 'part of the team' framework. However, the group would discuss in advance which aspects of the experience could be highlighted as representative of broader collective issues that resonate across many people's experiences. Returning to the widespread issues mentioned above, the impact of waiting times, noise on the ward, issues with parking, and feeling dismissed by staff members figured in many group members' experiences, so highlighting one of these issues through an individual personal narrative was an opportunity to speak on behalf of the group. There was concern that it should not just be the person who 'shouts the loudest' who got to report their experience to the board, and not all group members were ultimately able to take their turn. Sometimes the trust would understandably have a specific priority they wanted to discuss at the hospital board meeting (e.g., experiences of a labour ward during COVID-19 lockdown), though this experience was shared with the group to keep the emphasis on the collective idea of experiences. However, since the framework had not been sufficiently adopted and integrated into the process by senior management, this meant that that experiences were still sought without use of the 'part of the team' framework.

Additionally, some videos were recorded by the group but were never shared with the hospital board due to scheduling and communication issues. One contributor, who had approached the group with some distressing experiences to be shared to the board, felt that the process of being heard by Rachel and Jessie was in itself a positive

experience—of being given the space to tell their story in full, with attentive listeners. This patient and a supporting governor from the trust both described this process as "cathartic," despite the fact that these experiences were not ultimately shared with the board to effect structural change. However, a different contributor, whose video was not shared, was upset that their experience had not been heard by the board—they experienced participation as a promise to effect change that went unfulfilled. Without a better-established relationship with a dedicated member of staff at the trust, there was little the group could do to remedy this by liaising and scheduling when to share the video. The group itself was therefore not always 'part of the team'—similarly encountering a mixture of positive and negative experiences as part of the engagement process.

What we learnt

Videos were used as the vehicle for patient experiences and shared with the hospital's executive board since the group started meeting in 2019. These were very well received, sparked critical discussion among patients and staff, and prompted discussion at a senior level which resulted in commitments in the trust's 'Quality Report.' Prior to the pandemic, Rachel began exploring the prospect of generating a self-sustaining 'critical mass' of patients for the group to continue and started considering ways of increasing access. For example, she talked with a group of patients with learning difficulties through a different format to produce feedback through the 'part of the team' framework that was more accessible to their participation. While new patients joined the group, however, subsequent meetings saw drop-off in attendance from some patients (due to scheduling clashes). After one online meeting in Autumn 2020, staff changes and COVID-19 pressures disrupted communication between the trust and the group facilitators to the extent that it was not possible for the group to continue meeting; the processes were not sustainable or resilient enough to make it possible for the group to proceed without input from the trust. There is, however, plenty to learn from this experience to safeguard future initiatives against this kind of disruption. (Indeed, the process of getting feedback from group members on this article has brought to light several ideas that might be used in future projects. It is a shame that there is no longer a medium for taking these ideas forward at this particular trust, but it is worth noting that the process of reflection does not necessarily stop once these projects are ended.) In terms of changes effected by this particular project, it is worth noting that the 'part of the team' framework had already impacted staff training, policy enabling PPI participants to claim expenses from the trust, and the trust's 'Quality Report.' While it is difficult to stake specific claims to having effected structural change as a result of this project, these outcomes do indicate some traction and potential and they

show that the project was not merely a ‘listening exercise.’ It is on this basis that we offer some concluding reflections here.

Even though patient engagement in other settings will look different, based on contextual conversations,⁴³ we believe that it is possible to learn from structural similarities between health institutions and their administrative processes.⁴⁴ Our ‘lessons learnt’ will likely pertain to future endeavours in other settings due to these structural similarities; processes underpinning support and obstacles will be similar, even if patient priorities may importantly differ. However, there is always a balance between creating the right conditions for involvement and preserving the necessary openness for the process to emerge in response to the needs of those we seek to involve.⁴⁵ We therefore argue that meaningful feedback mechanisms in healthcare settings require institutional commitment to creating the conditions for listening and genuinely sharing power with patients, so that they really are part of the team.^{46,47}

Lessons learned

Collective voice

Patients had begun to consider commonalities across their individual experiences and to critically question the dynamics by which the hospital solicits feedback. In recognising elements of their own experiences in other patients’ stories, the seed had been sown for collective or composite storytelling. While the ‘part of the team’ narrative framework requires very little external infrastructure, it offers much more than simple means to ‘tell stories’; when sufficiently linked into receptive feedback mechanisms, a process like this makes it possible for patients to collectively challenge those with the power to effect change. It also moves beyond the tendency to keep groups of patients with experiences of a particular specialism separate, which again changes the dynamics of how patients see their position.

Accessibility

The process highlighted the need for NHS trusts to invest in patient involvement if the process is to become sustainable and accessible. As a direct result of this project, for example, patients are now compensated in recognition of their participation, after it was highlighted that there was no formal hospital policy for remuneration or expenses pertaining to patient involvement. We recognised from the beginning that some patients have particular circumstances or needs, and that it is important their stories are also shared to the board. Concerted efforts to diversify contributions to the group in this vein must be matched with an open and flexible approach to accessibility and inclusivity. Active evaluation of accessible participation is key—not only in terms of diverse attendance at group meetings but also in terms of roles

and decision-making—and especially regarding the inclusion of those with protected characteristics.⁶

Administrative support

In order to facilitate a truly accessible process, the patient engagement needs to be supported with resources and not only with words. Costs relating to travel, internet access reimbursement, refreshments, and any other accessibility requirements (e.g., interpretation, translation, and facilitation) need to be built into plans from the outset in such a way that they can flexibly accommodate individual needs. Dedicated administrative support is crucial, so that there is a clear point of contact with sufficient power to respond to the needs of the group. We experienced delays in relaying responses from the executive board back to patients who contributed stories, as other issues had taken priority in administrative workloads. As mentioned above, patients highlighted in initial meetings that their willingness to share their stories was conditional on their knowledge that a given feedback process is effecting change; timely responses are key to retaining patients’ trust and investment in the process. Dedicated administrative support could more effectively streamline communication between all parties as a priority.

Senior staff buy-in

While hospital administration readily supported our meetings, dedicated staff with clearer roles and responsibilities would be crucial to the longevity of future projects. It is impossible to establish dedicated administrative support without senior staff buy-in to approve resources and staff time allocation. Buy-in from senior staff also makes it possible to significantly amplify the impact of any group decisions. In our case, for example, the ‘part of the team’ framework was adopted for use in training nurses directly as a result of senior staff participation and support for the process, to highlight the importance of perceived agency for patients in hospital care. The patient-led framework was also published as a ‘Trust Priority’ in the 2019-2020 ‘Quality Report,’ with the aim of establishing a ‘critical mass’ of stories and participation to facilitate trust-wide learning. Disruption due to COVID-19 and staff changes curtailed these efforts, but the implications of senior-staff buy-in for education, policy, and practice should not be underestimated. It is crucial, however, that group processes are not dependent on gatekeeping to communicate about patient experiences and accordingly effect change.

Engaged facilitation

Meaningful patient involvement and engagement rarely comes directly from people telling you something. That said, however loosely, there needs to be a reason for gathering and sharing experiences; it needs to be clear to patients why we are working together and why it will be worthwhile. Engaged facilitation therefore needs to strike a

balance between honesty around limitations and structure and the risk of closing down the sense of possibility for participants (e.g., “We need stories to influence the hospital board... but after that it’s all up for grabs if we can get the planning right.”). There is also another important consideration to bear in mind when facilitating a process like this: who does it really serve? Can it serve an NHS Trust and patients equally?

Disclosure statement

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