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Connections: The Power of Learning Together to Improve Healthcare in the United Kingdom

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> *"It's your job, but this is my life"*
> *Cherelle Augustine, Improvement Leader Fellow and Service User*

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Introduction

Patients are essential to the transformation of care and health organizations. There are well-established service user movements in the UK which advocate for a stronger patient and public voice and draw attention to inequalities in health and discrimination in services. Policy publications refer to the desire for and perceived value of patient and public involvement (PPI). Meaningful PPI requires a systematic approach underpinned by emergent and experiential learning to generate evidence of what works well. Practice should demonstrate inclusivity and mutual respect.

This chapter is organized into three parts. Part one summarizes the background to the National Health Service (NHS) in the UK, drawing attention to the emergence and strengthening of the patient voice in contemporary healthcare. Part two reports our PPI practice within the context of an applied health research programme over ten years, drawing attention to three lessons gained through emergent and experiential learning. Part three shares personal reflections from service users and patients who are involved in improving care. The conclusion summarizes important messages from all three parts.

The History and Grassroots of Patients Voice in the United Kingdom

The National Health Service and the Voice of Patients

The NHS in the UK celebrated its 70th birthday in 2018. Introduced by the Labour government in 1948 as the country was recovering from war,

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approach to the dissemination of research and scientific enquiry. Here, we invite new voices to our chapter. They share their reflections, either directly or in partnership with chapter co-authors. We organize the section by grouping the reflections under four of the five main habits of an improver (see the following textbox). We suggest that each of these individuals possess all five habits, and we group stories to share a snapshot of insight. All contributors exhibit resilience in their personal circumstances and in encounters with the healthcare system, when seeking to promote improvement.

Creativity: Jean Straus

Jean is an improvement leader fellow who draws on her professional background in education and her experience of sudden hearing loss to raise awareness of this condition in the healthcare system. She promotes the use of visual formats and innovative participatory approaches, for example hackathons, to generate better insight and empathy between people.

> *I became involved in improvement work as a result of developing an isolating condition, idiopathic sudden sensorineural hearing loss. In medicine and research, I found little to help me understand what I had to live with. In my search for knowledge I gradually became aware of greater issues, of being a patient, having hearing loss, deafness, tinnitus, and age.*
>
> *I realised by sharing my experience I might be able to help others. I went from having dizzy spells and getting hearing aids, to writing book reviews for*

themselves or others to be detained with or without their consent, leading to concerns about patients' rights. Priority areas for health improvement were identified as cancer, coronary heart disease, mental health, HIV/AIDS, and inequalities in health outcomes. Those affected by HIV and AIDS organized and campaigned for research and better treatment, ushering in an activism not commonly seen in the UK at the time (Manganiello and Anderson 2011).

Consumerist ideology became more influential in the 1990s and the Patient's Charter introduced in 1991 (Department of Health 1991) set out patient rights and expectations in service areas including GP services, hospital services, and ambulance services. Patients were invited to provide feedback and NHS organizations could be nominated for a Charter Mark if exceptional care was provided. In 1997, a new Labour government was elected and by 1998 health policy was decentralized through devolution in Scotland, Wales, and Northern Ireland (Greer 2008).

In 2001, Professor Ian Kennedy published *Learning from Bristol* (Kennedy 2001), documenting failures in children's heart surgery at the Bristol Royal Infirmary and the attendant disregard for parents who raised concerns. The report served as a blueprint for wider NHS reform and provided the impetus for renewed policy and legislation agendas such as the 2001 Health and Social Care Act and the publication of the NHS Plan. The NHS Plan set out an ambitious plan of reform developing further choice and competition (Department of Health 2000). It intended to strengthen the accountability of the NHS to consult with patients and the public. Foundation trusts were created with membership boards to which the public could be elected. Patients were increasingly viewed as informed consumers who are able and willing to make choices within the system. However, this was not borne out in practice, with the Acheson Report (Acheson 1998) recognizing continued concern about inequalities in relation to socioeconomic position, ethnicity, and gender.

The NHS Constitution for England (Department of Health 2009) sets out the rights for patients, public, and staff in the NHS. Regulatory and inspection mechanisms such as the Care Quality Commission (CQC) were set up to monitor services and provide an independent voice for people. The coalition government elected in 2010 reinforced their commitment to engaging the public through the Five Year Forward View

(NHS England 2014), and the 2012 Health and Social Care Act resulted in significant service restructuring. It reinforced the duty to consult and involve patients and the public in the commissioning, delivery, and evaluation of services. In 2019, NHS England published the NHS Long Term Plan (NHS England 2019), setting out the strategic direction of the health service for the next ten years. The NHS Long Term Plan (NHS England 2019) is perceived by some commentators (Beresford 2019; Denegri 2019) as a missed opportunity to build on the maturing patient and public involvement movement. Despite policy commitment, failures in care suggest that patient and carer voices can still struggle to be heard.

Patient and Public Involvement (PPI) in the NHS and Publicly Funded Research in the United Kingdom

The UK and other countries including Australia, Canada, Demark, Norway, and Sweden (Boivin et al. 2010; Wiig et al. 2013; Farmer et al. 2018) have maturing movements and commitment to the involvement of patients, carers, and service users in the design, delivery, evaluation, research, and improvement of healthcare (INVOLVE n.d.). The involvement of patients, the public, and citizens is not a new concept in the UK (Hogg 2007; Coulter 2011; Barnes and Cotterell 2012). There is a history of user movements which have influenced aspects of health in both service provision and research, for example, in mental health and disability (Beresford and Branfield 2012; Hallsor 2017; Terrence Higgins Trust n.d.). This difficult and pioneering work is recognized. However, it can be easily obscured by the proliferation of policies, toolkits, political ideology, and frequent and fragmented health service structural reform.

Hogg (2007) provides a useful account of the seismic changes in England introduced by the abolition of Community Health Councils (CHCs). CHCs were introduced as state sponsored scrutiny arrangements in 1974 and abolished in 2003. The councils were initially replaced by Patient and Public Involvement (PPI) Forums, followed by Local Involvement Networks (LINks) in 2006 and subsequently by Healthwatch England in 2012. Healthwatch England is described as ‘the independent national champion for people who use health and social care services’

(Healthwatch n.d.), with a Healthwatch in each of the 152 local authority areas in England. They are funded by central government and administered through the local authority. Healthwatch is therefore affected by the economic and fiscal policies of the elected government.

There are different statutory arrangements for the involvement of patients and the public in Wales, Scotland, and Northern Ireland. Wales introduced a Board of Community Health Councils in 2004 (Community Health Council n.d.). Their role is to enhance and improve the quality of local health services. In 2015, the regulations were updated to give the board responsibility for setting standards for the local councils and to monitor their performance. In Scotland, the Scottish Health Council (Scottish Health Council n.d.), established in 2005, promotes improvements in the quality and extent of public involvement in the NHS in Scotland. NHS Boards in Scotland have a statutory duty to involve patients and the public in the planning and delivery of NHS services. In Northern Ireland, the 2009 Health and Social Care Reform Act placed a statutory duty on health and social care organizations to involve and consult patients, families, carers, and communities in the planning, delivery, and evaluation of services (Department of Health Northern Ireland n.d.). In Northern Ireland, PPI refers to personal and public involvement, with the Public Health Agency responsible for implementation of policies.

In health and social care research, there is an established support organization in England, INVOLVE, funded by the Department of Health and Social Care and hosted by the NIHR. INVOLVE emerged from the Consumers in NHS Support Unit established in 1999 which developed from the 1996 Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme (Evans 2014). The creation of the NIHR in England in 2006 and the appointment of the first NIHR National Director for Patients and the Public in Research in 2012 intensified interest and activity. The first national review of PPI across the NIHR in England was conducted and published as *Going the extra mile: Improving the nation's health and wellbeing through public involvement in research* (National Institute for Health Research 2015; Staniszewska et al. 2018). This report recommended exploring the nature of co-production in research. It summarized recommendations to guide strategic direction of PPI in research over the following ten years under four areas:

(1) Reach—to widen involvement across the diverse population.
(2) Relevance—minimize waste by ensuring research is grounded in the problems faced by people living with health and social care needs.
(3) Refinement—to continuously learn and improve practice.
(4) Relationships—to keep the focus on involvement relationships which transcend the politics, policy, and structural maelstrom to seek new insight and knowledge.

Academic debate explores the difficult relationship between theory, policy, and practice and the differing perception of and variation in impact (Martin 2009; Tritter and McCallum 2006; Gibson et al. 2017; Madden and Speed 2017; Hickey 2018).

Involvement in Healthcare Improvement

High-profile care failures in England suggest that there are persistent barriers to learning *with* patients about what needs to be improved (Francis 2013; Kennedy 2001). This may in part be due to the complex and challenging healthcare landscape in which the patient and carer perspective can quickly become obscured. Further progress is required to evolve from a system characterized by paternalism and institutional power towards collaboration and networks (Malby and Anderson-Wallace 2017). Efforts are being made to foster a change in culture that recognizes the potential for patients and healthcare professionals to work more closely (Berwick 2016; Batalden 2018; Seale 2016; Pereira and Creary 2018).

NIHR CLAHRC Northwest London works from the INVOLVE definition which describes involvement as any activity that is done ‘with’ or ‘by’ patients and not ‘to’ ‘for’, or ‘about’ them. Other terms are used, sometimes interchangeably, for example ‘engagement’ and ‘participation’. The INVOLVE definition is helpful to facilitate research and improvement teams and with individuals to clarify what they want to achieve. Involvement can take place at different levels. Carman and colleagues (Carman et al. 2013) offer a useful framework to conceptualize involvement at individual, service, and policy level. This framework uses a continuum to indicate how power can be shared between professionals and patients from consultation to partnership. In recent years, more attention has been paid to the idea of co-production suggesting a move towards an acknowledgement of and reduction in power differentials. Batalden and colleagues (Batalden 2018; Batalden et al. 2016) emphasize the uniqueness of the healthcare setting when exploring the concept of co-production and the necessary understanding and trust that are required to achieve shared planning and execution of services. Filipe et al. (2017) explores co-production as an experimental space. Whilst involvement in healthcare is not new, disquiet is being expressed about persistent barriers and constraints (Ocloo and Matthews 2016; Wicks et al. 2018; Gilbert 2018; deBronkart 2018; Batalden 2018). In part two, we share learning about how some of these challenges can be approached despite the complexity of the policy, evidence, and structural landscape.

Patient and Public Involvement Practice Within the Context of an Applied Health Research Programme

Applied Health Research: An Unusual Space to Foster Involvement

In 2009, the NIHR introduced a competitive infrastructure funding call inviting partners from the NHS and academia to secure funding to speed up the translation of research evidence into everyday practice to benefit patients (Cooksey 2006). The aims of the CLAHRC programme in England funded from 2013 are set out in the following textbox.

The NIHR CLAHRC Northwest London programme presented an unusual space for the involvement of patients, carers, and service users in quality improvement and the translation of research evidence into practice. The NIHR CLAHRC programme does not commission or provide health services and is heavily reliant on effective partnership working between the NHS, Higher Education Institutions (HEI) and Third Sector, and community organizations.

Aims of the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Programme

- **Develop and conduct applied health research** relevant across the NHS and translate research findings into improved outcomes for patients
- Create a **distributed model** for the conduct and application of applied health research that links those who conduct applied health research with all those who use it in practice **across the health community**
- Create and embed approaches to research and its dissemination that are specifically designed to take account of the way that healthcare is delivered **across the local Academic Health Science Network**
- Increase the country's **capacity** to conduct high-quality **applied health research** focused on the needs of patients, particularly research targeted at **chronic disease and public health interventions**
- **Improve patient outcomes** locally and across the wider NHS
- **Contribute to the country's growth** by working with the life sciences industry

Source: National Institute for Health Research (2016)

NIHR CLAHRC Northwest London was the first programme of its kind in the capital and one of nine funded across England in 2009. It secured further funding from 2014 when the number of CLAHRC programmes increased to 13.

NIHR CLAHRC Northwest London made an explicit commitment to involve patients, carers, and service users in its activity from the beginning, building this into all levels including governance, shared learning, and local improvement research funding calls. From the outset, our programme combined practice with research. A partnership was established with social science researchers at the London School of Hygiene and Tropical Medicine. This unusual combination enhanced our ability to practise and study involvement in a variety of settings across acute hospital, primary and community care. We describe emergent learning that evolved our practice and provided data for ethnographic research (Renedo and Marston 2015a, b). It is worth noting that as a research programme funded for two consecutive five-year periods between 2008 and 2018, our position, by comparison with other healthcare organizations in our local health system, has been stable. During this period, there were two general elections, four acute (hospital) NHS trusts in northwest London merged into two organizations, and the health reforms of 2010 changed the commissioning and public health landscape. Our research programme remained a constant with a limited turnover in team membership. This is an important factor which supports the development of work and relationships over time. Next, we draw attention to three important lessons about the foundation of meaningful PPI practice from 'doing'.

Emergent and Experiential Learning

Learning by doing, gaining experiential knowledge, and being alert to emergent understanding is a significant and distinguishing feature of PPI in our programme approach. Emergent learning is described by Darling and Parry (Darling and Parry n.d.):

> *Learning from experience is mostly done retrospectively. Engaging in emergent learning means taking an intentional, evolutionary approach to learning 'through' experience—by conducting iterative experiments using a group's real work as the experimental field. Taking this approach often produces new and powerful learning simultaneously to making headway on key business issues.*

We report three significant lessons from this approach at NIHR CLAHRC Northwest London. These lessons may be unsurprising but we propose that they reflect the overlooked work of involvement that needs to be better attended to in practice and more fully explored in research:

1. Establishing connections and relationships—the need to make connections and build relationships over time from which shared improvement and transformation interests can be identified.
2. Democratizing learning spaces—include learners without professional or employment status and loosen the traditional rituals and practices that influence and characterize learning in healthcare.
3. Testing frameworks in practice—rather than creating something new, test and adapt existing evidence-based frameworks to understand acceptability and utility in the real world.

Lesson One: Establishing Connections and Relationships

From the outset, we communicated the purpose of NIHR CLAHRC Northwest London to the wider community and identified potential opportunities for people to be involved. Working in partnership with InHealth Associates, a consultancy dedicated to the promotion of patient and public engagement and involvement, and later with the Centre for Patient Leadership, we offered a free learning programme called 'The Effective Patient and Community Representative' to support people who wanted to be influential in improving healthcare services. We approached local NHS, third sector, and community voluntary organizations to recruit participants. The programme ran five times between 2009 and 2012 enrolling a total of 76 patients, service users, and community representatives. It differed from traditional, episodic deficit-model induction and introductory courses and focused instead on working with the experiences and skills participants brought with them and what they wanted to achieve. Each programme had four consecutive monthly sessions. This approach established peer relationships over time and enabled facilitators and participants to work together to identify further opportunities for collaboration.

Three important outcomes emerged from this experience. First, programme participants alerted us to a community-based idea focused on people living with diabetes—Diabetes Improvement through Mentoring and Peer Led Education (DIMPLE)—that we subsequently funded (Chita et al. 2012). Second, some participants were invited to critique their learning experience and in doing so challenged our inclusion criteria for our Improvement Leader Fellowship launched in 2010. Third, summative participant evaluation suggested we consider co-designing a new opportunity where patients, carers, and service users could learn more collaboratively *with* clinicians, researchers, and managers. They expressed a desire for a *shared* learning space. This influenced the development of the Exchange Network which is described in lesson two.

Lesson Two: Democratizing Learning Spaces

The way people come together, and how they learn, can model and reinforce collaborative behaviour (Clarke et al. 2018). Education and training in healthcare, whilst varied in style and delivery, is generally characterized by scientific expertise and influenced by professional history and culture. Time and resource constraints often lead to transactional, rather than transformational, experiences (Britto et al. 2018; Budrionis and Bellika 2016; Nelson et al. 2016). As patients and carers became more involved in the work of the NIHR CLAHRC Northwest London programme, we recognized limitations in this traditional approach, and the nature and qualities of our learning spaces changed over time. We share four examples: (a) the use of open space technology at events; (b) the move to an inclusive Improvement Leader Fellowship; (c) collaborative learning events; and (d) the development of the Exchange Network.

Open Space Technology: Sharing Power

In the first two years of funding, NIHR CLAHRC Northwest London held events focused on PPI. These followed a conventional approach with invited speakers and limited discussion opportunities which became frustrating for all parties. One participant suggested using Open Space Technology (Owen 2008) as an alternative approach. The approach is designed to support groups to self-organize around a specified theme to tackle complex issues in a time limited period. It means identifying a theme that a diverse group of people can relate to and inviting them to spend time exploring related issues in order to generate new insight and fresh ideas. Working with facilitators from the Participation Agency, we tested Open Space Technology. Instead of NIHR CLAHRC Northwest London controlling or feeling responsible for an agenda, participants were invited to explore themes posed as a question at two events in 2011 and 2012. Participants designed the agenda during the event, self-organized around issues raised on the agenda, and reported their reflections, ideas, knowledge, and actions by the end of each event. A democratic process completed each event by enabling all participants to vote on the most important ideas or actions that emerge for further attention. The practice of co-production was promoted by one participant in our 2011 Open Space Event and was validated through the voting process. The experience of participating in a different group dynamic suspended familiar hierarchy temporarily and enabled more diverse insight to emerge. The use of Open Space Technology revealed a shared appetite in our community connections to work more creatively. As a result of this experience, our style shifted from 'telling' and operating as 'experts' to one which 'asks' more questions and seeks broader expertise.

Improvement Leader Fellowship

The Improvement Leader Fellowship programme was launched in 2010 to build capacity in improvement science with our organizational partners. Nine cohorts have completed the programme since 2010 in Northwest London. The year-long fellowships developed leadership skills for quality improvement (QI) through a work-based project (12–15 multidisciplinary fellows each year, including patients) (Myron et al. 2018). Participants from the 'Effective Patient and Community Representative' programme challenged us to open the fellowship to patients, carers, and service users from 2012. Over 55 improvement initiatives and 118 individual fellows were supported over nine years of the Northwest London programme. One of the core criteria and common features of the fellowship is 'in person' learning sessions, which enable shared learning on QI approaches and evidence-based interventions and include collaborative shared learning where the patient perspective is a key contribution.

The fellowship is designed to be a participatory space (Renedo and Marston 2015b) where professionals and patients' knowledge both shape and are shaped by the participatory spaces created by the fellowship. It is a novel empirical case as it is designed for patients and healthcare professionals to learn together. The fellowship is modelled on collaborative learning theory, which suggests that social interaction is an integral part of learning, and multiple perspectives strengthen this process. Participants on the fellowship programme are drawn from varied backgrounds. They include patients and different professional groups with diverse research interests and educational attainment. The fellowship is unique, in that it is the only programme to our knowledge that engages and integrates patients as well as professionals in joint educational development. In part three, you can read reflections from some of the patient and service user fellows.

Collaborative Learning

The experience of delivering the 'Effective Patient and Community Representative' programme and testing Open Space Technology reinforced our ethos of collaboration, especially in learning. A collaborative approach to learning emphasizes the role social interaction plays in cognitive development and effective learning (Vygotsky 1997). Learners benefit from understanding a range of perspectives on real-world problems which are best developed through interactions and experience rather than didactic modes of teaching (Reeves et al. 2017).

In healthcare, the features of collaborative learning include small group work, peer problem solving discussions (Marsick et al. 1999), and learning within a 'real-world' context (Barkley et al. 2004) where the role of faculty is to facilitate rather than 'teach'. The patient perspective is key in understanding the real-world problems faced and the real-world context. Knowledge exchanges are not static but are shaped by an individual's professional and personal priorities, drawing on a range of 'knowledges' and past experiences to inform decisions in healthcare practice (Dixon-Woods 2018).

A key feature of quality improvement initiatives is facilitating dialogue between groups from different backgrounds (Busari et al. 2017) and a collaborative learning approach encourages shared learning between groups (Anderson et al. 2017). This learning involves both the 'technical' (e.g. learning tools such as process mapping and Plan-Do-Study-Act cycles) and the 'social' (e.g. influencing, problem solving, and empathy) skills of quality improvement needed to create and sustain improvements (Godfrey 2013; Lucas and Nacer 2015).

As part of the NIHR CLAHRC Northwest London programme remit to build capacity, we create frequent opportunities for our improvement community to connect, share learning, and collaborate. The improvement collaborative events feature a combination of plenary and breakout sessions and involve attendees from different professional groups. Patient inclusion in such groups brings a richness and reality to the discussion, enabling participants to understand the real-world context in a more effective way. Thirty-five events have been held between 2009 and 2018, with 1384 unique individuals attending from different backgrounds, including healthcare professionals (67 per cent), researchers (15 per cent), and patients and carers (6 per cent). Attendees reported gaining and subsequently using QI knowledge and that peer-to-peer learning about QI methods and opportunities to meet new people afforded by the events were beneficial to improvement work. Collaborative learning approaches through a series of events not only support the development of QI skills, particularly those relating to relationship building and behaviour change, but also support the development of a community and wider network. Patients, carers, and service users are essential to that network.

The Exchange Network

The Exchange Network emerged from dissatisfaction with tokenistic engagement and involvement practice across healthcare experienced and witnessed by a group of patients, carers, researchers, and team members at NIHR CLAHRC Northwest London. There was a desire to create a shared learning space. Open Space Technology (Owen 2008) was the catalyst which changed the nature of conversations and enabled co-production to be promoted and championed by service user Alison Cameron. The value of co-production is often championed by individuals with experience of being let down by a healthcare system that is perceived as reluctant to see the person in the patient with skills, experience, and attributes to support improvement in care. The Exchange Network emerged in late 2013 to address this concern. A small group of patients, carers, service users, and members of the NIHR CLAHRC Northwest London team convened to explore and shape ideas that could be co-designed and tested in practice. The aim and objectives of the Exchange Network emerged through question-based enquiry with support from a third-party facilitator.

Aim and Objectives of the Exchange Network

Aim

To co-design an inclusive network, underpinned by principles of co-production for shared learning in involvement, improvement, and research

Objectives

(1) Eliminate tokenistic practice
(2) Create a space that fosters mutual trust
(3) Model effective dialogue and shared learning
(4) Notice and respond to power differentials
(5) Provide peer support
(6) Connect patients, carers, clinicians and researchers, and others with interest in involvement, improvement, and research
(7) Identify and create inclusive opportunities for personal development
(8) Influence the practice of involvement, improvement, and research

The Exchange Network developed iteratively in line with the principles underpinning improvement at NIHR CLAHRC Northwest London (Reed et al. 2018). The defining features of the Exchange Network emerged from a combination of testing a structure and process in practice.

Defining Features of the Exchange Network

- The Exchange Network gathers in a community venue, not an institutional setting
- It is co-facilitated by two members, ideally with different backgrounds
- The day opens with introductions by first name and not by title
- The discipline of dialogue underpinned by the ladder of inference (Argyris 1982; Ross 1994) guides all interaction between the network—asking open questions, resisting judgement, checking assumptions, and reflecting on personal beliefs and feelings to help self and others
- Asking for and offering help with an issue or task in the spirit of shared learning
- Engaging with action learning (Revans 1982) to advance personal reflection and expand potential course of action
- Offering and receiving peer support and engaging with networking
- Time: the Exchange Network meets for five hours four times a year

The Exchange Network has sustained for five years and grown from 13 to 68 members. No previous experience or skills are required of members.

The inclusion criteria require just two commitments from participants which are mutually identified with prospective members before they join their first meeting: a desire to learn with people from different backgrounds and expressed comfort with emergent rather than concrete learning. The meetings offer a framework for further co-design and collaborative effort. Tokenism is resisted. Mutual trust is built through the careful preparation and explanation of what will happen and how and continuous reflection by all participants. The role of co-facilitation is critical to achieve this and is constantly monitored to ensure trust is maintained, without which the quality of conversations and interactions would be compromised. Difficulties are attended to in the moment or immediately after the meeting. The Exchange Network tests the possibility of co-designing a democratic learning space that fosters mutual trust in the process (Filipe et al. 2017; Matthews and Papoulias 2019).

Lesson 3. Testing Frameworks in Practice

There is a proliferation of toolkits and guides about PPI. Whilst there are policy and legal incentives to involve patients in quality improvement, making it happen in practice can be challenging. The example in this section describes the use of a framework to take a deliberative approach in co-designing the roles that services users played in an improvement project. The mortality of people with serious mental illness (SMI), such as schizophrenia and bipolar disorder, is greater than the general population, accounting for a 15- to 20-year difference in the UK and representing one of the most significant health inequalities in society (Chang et al. 2011; Miller and Bauer 2014). This has been attributed to the increased prevalence and impact of respiratory, cardiovascular, and endocrine disorders. Whilst the underlying causes are not fully understood, they are associated with potentially modifiable risk factors linked to the environment and lifestyle.

In order to address this issue, a QI project was established within an acute mental health setting, supported by NIHR CLAHRC Northwest London, to design and implement a physical health pathway. The multi-professional team was led by a consultant psychiatrist and consultant psychologist who recruited a number of service users to the team to provide

Table 6.1 4 Pi framework

Principles	Clear and shared principles and values
Purpose	Agreed purpose of involvement linked to the improvement or research of services and patient experience
Presence	Involvement of patients at multiple levels and stages of an initiative
Process	Communication and support to ensure engagement with patients, carers, and patients
Impact	Assessment of the effect of involvement on both the individuals and the initiative

Source: Faulkner et al. (2015)

input and insight into the potential solutions that the team developed. Many approaches have been developed and promoted for the involvement of patients in the design, delivery, and improvement of services and applied health research. Despite the dissemination of such approaches to involvement, their application in QI, especially related to the impact of involvement, has rarely been reported (Mockford et al. 2012). Whilst it might be said there is no right way of engaging patients, frameworks and approaches are available to support the process. At NIHR CLAHRC Northwest London, the 4Pi framework (Table 6.1) was adopted as one such approach to be tested and to guide the involvement of patients in QI projects (Faulkner et al. 2015).

The 4Pi framework should inform the development of a plain English 'involvement proposal' and 'role descriptions' for patients, which sets the tone for early discussion with, and recruitment of, patients into the QI or applied research team. The involvement proposal and role description together addressed each of the 4Pi concepts, as follows:

Principles: Throughout the development and planning of the project, there should be clear commitments from senior members of the team to involvement of patients in a meaningful way. This could be with any number of (or all) aspects of the project including development, co-design of interventions and their subsequent implementation or the dissemination of learning. It helps to be clear about these principles, even if a precise plan isn't developed, as this may allow a more flexible way of working and support emergent opportunities for the whole team to be involved in decisions about the process.

Purpose: The team should be clear about the range of experiences, skills, and knowledge required by the project and ensure these are relevant to the everyday experience of patients and staff. Involving patients as equal members of the QI or research team is intended to achieve a more nuanced understanding of service user's experience by identifying groups and individuals not usually involved in this type of work to appreciate alternative explanations, interpretations, ideas, and perspectives. For many staff, this could be the first time they will have worked with patients as partners and could create a unique space where patients, healthcare professionals, researchers/QI specialists can work together.

Presence: The presence of patients may not be solely at the level of the project steering committee as advisors but may also include working directly alongside healthcare professionals/researchers to co-design interventions and/or support implementation. All team members, including patients, should be provided with clear aims of the project, if not involved in developing them, along with meeting schedules and details of responsibilities, expectations, and time commitments to ensure the presence and contribution of all those involved were clear and well-thought out. This ensures that all members of the team have sufficient information and assurance that the processes are accessible, transparent, and adaptable to support effective and meaningful involvement.

Process: Patients, like all project team members, should be invited to participate in regular team meetings and workshops, where a range of participatory methods should be used to provide a voice to all those present. The use of participatory approaches to involving staff and patients are intended to ensure the voices of all stakeholders are considered, to benefit the project, but also intended to provide skills and opportunities for patients to engage with healthcare improvement.

Impact: The involvement of patients in the project should have a direct impact on the project itself, according to the stage and level of involvement. This might depend also on the engagement of patients and staff in the success of the various participatory methods and their ability to empower those involved. However, impact may also be seen at individual level, on the patients that were involved and/or the staff that have had the unique opportunity to work alongside these patients.

At the individual level, staff expressed the impact that involvement of service users had had on them:

> *Involving service users in our project has been critical. As well as improving the outputs and outcomes of the project, their presence has had a real personal impact. Meeting with people who have used our services not as patients, but as colleagues has been genuinely thought provoking, helping to focus our thinking on end benefits to people using our services. It has also been really rewarding to see how the process has been beneficial to service user colleagues—personally for us as team members and leaders, but also in terms of knowing that we have played a part in supporting the development of people who will go on to contribute to other healthcare projects and quality improvement initiatives. And it has helped to bring a more 'human' feel to the project overall—where we have all been able to leave our professional roles and hierarchies at the door and work constructively together.*

Further detail about the use of 4Pi in this project is reported by Green and colleagues (Green et al. 2016). In part three, you will read a range of personal reflections about the contributions patients and service users bring to the improvement of care and healthcare organizations.

Personal Reflections of Involvement for Improvement

The striking aspect of our learning since 2009 is the value of collaborative relationships which develop over time. The exchange of insight, knowledge, and experience has enriched our programme. In this section, we respond to the challenge posed by Professor Bill Lucas to use 'The Habits of an Improver' as a framework to explore new ways of learning about improvement (Lucas and Nacer 2015). We propose that patients, carers, and service users possess many of the improvement attributes identified including the mathematical and scientific habits and skills to build learning power. We suggest that these attributes are mislaid, dismissed, or discarded through bureaucratic processes and tokenistic practice. Publishers, for example the British Medical Journal, are pioneering a more inclusive approach to the dissemination of research and scientific enquiry. Here, we invite new voices to our chapter. They share their reflections, either directly or in partnership with chapter co-authors. We organize the section by grouping the reflections under four of the five main habits of an improver (see the following textbox). We suggest that each of these individuals possess all five habits, and we group stories to share a snapshot of insight. All contributors exhibit resilience in their personal circumstances and in encounters with the healthcare system, when seeking to promote improvement.

The Habits of Improvers

1. Creativity
2. Influencing
3. Learning
4. Systems thinking
5. Resilience

Source: Adapted from Lucas and Nacer (2015)

Creativity: Jean Straus

Jean is an improvement leader fellow who draws on her professional background in education and her experience of sudden hearing loss to raise awareness of this condition in the healthcare system. She promotes the use of visual formats and innovative participatory approaches, for example hackathons, to generate better insight and empathy between people.

> *I became involved in improvement work as a result of developing an isolating condition, idiopathic sudden sensorineural hearing loss. In medicine and research, I found little to help me understand what I had to live with. In my search for knowledge I gradually became aware of greater issues, of being a patient, having hearing loss, deafness, tinnitus, and age.*
>
> *I realised by sharing my experience I might be able to help others. I went from having dizzy spells and getting hearing aids, to writing book reviews for*

> *the magazine of the charity Action on Hearing Loss, to giving talks to Rotary and other groups about hearing loss and speaking to and blogging for the MRC (Medical Research Council). I was invited to represent the patient view on a James Lind Alliance steering group on research priorities for mild to moderate hearing loss. Awarded a NIHR CLAHRC Northwest London Improvement Leader Fellowship, I began focusing on the challenge of hearing loss in care homes.*
>
> *What does all this mean, to healthcare and to me? I have been given platforms where I can raise often-ignored hearing loss issues within the context of health care. I have discovered and supported numerous related healthcare issues, such as hearing loss in acute wards, acoustics in hospitals and care homes, ageism, dementia and hearing loss, mental health and hearing loss, tinnitus, and lately patient involvement in healthcare.*
>
> *Age 76, I am affiliated with researchers and clinicians in multiple fields, known to them, published by them and able to call upon them. They call on me too, to give talks about who I am and what I have learned. The Fellowship has given me options of becoming involved and having a voice. The Exchange network has given me regular opportunities for exchanging ideas and working through dilemmas. The collaborative events have given me a larger community and the stimulating possibility of learning about work I never could have known existed. The methodologies and systems training by NIHR CLAHRC Northwest London have given me discipline and an understanding of how little one individual can do, and yet how much she can change just by trying. I've learned that in improvement projects, one starts with something small and builds on it in small increments. I like to think I exemplify the same process.*

Creativity: Laura E. Fischer

Laura experienced extreme personal trauma. Here she offers a glimpse of her insight. Laura is an Improvement Leader Fellow who uses film and non-verbal body-based approaches to convey the limitations of established methods to promote healing and to explore the possibilities of alternative approaches. She rightly challenges the label of 'patient' involvement.

> *When I heard of NIHR CLAHRC Northwest London, my work on psychological trauma had just begun to develop and take varied and tangible forms—I was yet to discover where exactly it would lead me, and little did I realise that the Improvement Leader Fellowship would be a key determinant in this. After*

years of struggle, battling complex Post-Traumatic Stress Disorder and severe depression following events of extreme interpersonal violence which propelled me into a dual reality where past and present blurred, living turned into survival, and home regularly gave way to hospital, I had gone far enough in my healing journey and was ready to open it to others. I stepped on a TEDx stage and, for the first time, publicly shared my story and used it as an opportunity to open a dialogue about trauma—today's most pervasive and unspoken public health threat. The limitations I experienced in therapy also pushed me to research the neuroscience of trauma and the way in which creative practices could appropriately reactivate the parts of the brain that are damaged by traumatic experiences, and how, based on this, new methods could be designed to improve our current treatments. I moved beyond the conceptual and began to develop a survivor-led body-based creative practice for the processing and communication of traumatic memories. It was clear to me that drastic changes were due in our approach to healing. NIHR CLAHRC Northwest London understood this and entrusted me with a fellowship.

Whilst I had not yet fully grasped the work of NIHR CLAHRC Northwest London and neither had they mine, our values were in line and we clearly shared the motivation to shift things for the better. The most powerful and beautiful aspect of our year together was that not only these values carried us through and the motivation continued to grow, but the relationship we created between faculty and fellows nurtured and expanded both our individual and collective approaches and formed but one whole movement of genuine and passionate improvement work. With time, we withdrew of the labels that separated us and allowed a blank canvas of diverse minds to challenge and inspire one another. My unconventional art and science background and my personal experience of trauma were valued, my disruptive and creative ideas were welcomed and even sought out, and eventually, through and with NIHR CLAHRC Northwest London, I became an active Improvement Leader. In addition to projects, I spoke at several events and conferences across the UK and beyond, from breakout sessions to keynote speaker—most importantly, I felt validated in my confidence to speak openly, without fear to tackle topics which some wish not to discuss, and with complete honesty. In other words, I became someone whose wild interdisciplinary work people may still not quite fully grasp, but that brings a certain productive disruption that many, like NIHR CLAHRC Northwest London, understand is due.

There are many other survivors, too, who are extremely keen on contributing in their own unique and powerful way. Their experiences, like my own, are not ones justly captured under the label of 'patient' or 'service user'. They are not

> *passive, they have survived what no manual could ever rightly capture—they are leaders; leaders of growth and leaders of positive change in a culture in dire need to be challenged. Their experience is their insight, and their insight is our asset.*

Influencing: Sandra Jayacodi with Stuart Green

Sandra plays an important role in promoting the physical health of people with serious mental illness. She is an improvement leader fellow. With this experience, she revisited the country of her birth to advocate for better mental health care. She was invited to the Malaysian Health Ministry and to be a plenary speaker at the International Society for Quality in Health Care (ISQua) 2018 International Conference in Kuala Lumpur. Here she describes her influence in the SHINE (Green et al. 2018) project described in part two.

> *Being part of the project, the team took on board what the service users were saying, for example, when I first became a member of SHINE, I was quite shy, I brought in a booklet from the British Heart Foundation called 'Everyday Triumphs—Mental Health Service Users', and this was accepted and included in the physical health information pack for patients. This gave me a lot of confidence that I could make a difference. I also suggested that the results of the patient's physical health assessment information should be given to them, as it belongs to them. This led to the development of the patient held physical health booklet, which we co-designed with healthcare professionals. All the feedback I gave was taken on board, and I felt yes, there was quite a lot of influence from that perspective. As a service user, I felt that being involved in the project has given me more confidence to work with professionals now. Also, when I go out and disseminate information about the project, from a service user perspective, people seem to pay a lot more attention and engage more, especially when I presented at the board of directors about the project. If the project didn't have service users, they wouldn't have the passion from the patients' perspective but also, the project itself has helped me understand my own continuous battle with my physical health, it's because of my involvement in the project I have been able to maintain my weight. Finally, I'd say it's important to not only recognise the input and involvement of service users but also provide support for them, when necessary.*

Influencing: Adrian Brown and Justin Baker

Adrian Brown is a nurse specializing in the care of people with addiction and alcohol dependency. Justin Baker is in recovery for alcohol dependency. Here Adrian shares his reflections about the influential conversations with Justin when they worked together on a project to improve the care for people admitted to an acute general hospital with alcohol dependency.

> *Our project focused on an issue for hospital patients that is often poorly understood by the two main clinical groups that will be called upon to support those patients. People who are alcohol dependent are more likely to attend Emergency Departments and to be admitted to hospital than average for their age group. Addiction is seen by many as a mental health issue, but the withdrawal symptoms require physical health treatment. Add to this, the too common opinion that alcohol problems are 'self-inflicted'. In setting up this project, our team listened to in-patients treated for withdrawals and people in recovery at the local addiction services.*
>
> *It was not easy to engage people in direct feedback at this difficult time, so focus groups at the local community services often revealed more about the negative experiences. Several themes emerged from those people: 'some staff attitudes are negative', 'most staff are compassionate but don't recognise the symptoms', 'we don't feel that we deserve to be in hospital'. The NIHR CLAHRC Northwest London [Exchange] network of people with experience of care was an inspiration. People who did not have experience of alcohol dependence understood that it's not always easy to become an 'expert by experience' but they had ideas and encouraged us to continue telling patients about the project.*
>
> *At one of the community focus groups, the project lead was approached by one of the people who had been treated in our hospitals—Justin. He said that he had nearly died due to acute pancreatitis, but the support and treatment of the Trust's gastroenterology nurses and medical colleagues—right up to the consultants—had encouraged him to get into rehab. Justin is now sober and helping people by being a peer mentor in the recovery programmes. He was keen to contribute, by telling his story as part of our training, and agreed to take part in our project groups.*
>
> *What Justin brought to the meetings was a perspective none of us had—what it is like to be on the receiving end of judgemental attitudes, of frightening symptoms and the compassion of nurses and doctors caring for them. What it is*

> *like to see people give up on you, but to be given a chance by a hospital team. We had no hesitation in involving Justin as a member of the quality improvement project team, with equal status to the clinical experts, the experienced nurses, and the hospital managers. He asked us questions that challenged our clinical familiarity and moved us towards a process that is understandable to all participants—ward staff AND patients. If only all systems projects were able to involve someone who knows first-hand what the benefits of improvement can be.*

Learning: Jenny Trite with Stuart Green

Jenny is a service user and experienced contributor to improvement and research. Drawing from personal experience and as an important member of the SHINE team, she reflects with Stuart Green on the very particular acquisition of new skills in improvement and what she has learned about herself in this process.

> *When I joined the SHINE project team I didn't have any experience in quality improvement but I had been involved in many research projects over the years. In the SHINE project, we all started out the same, learning together about quality improvement and designing the project, this is the first time I've really felt an 'equal' part of a team and as such have learnt so much about the process. After this experience, I don't know who or what I'm representing anymore …. I've definitely changed and to be truthful I'm not sure where I fit in anymore! The 'system' isn't really geared up for people like me who do not enter through the 'normal' pathways. Whilst being part of the project was a great opportunity and I learnt so much about myself and working with others opportunities for the future are less certain.*

Learning: Howard Bluston

Howard brings professional and personal experiences to support and advocate for people with Inflammatory Bowel Disease (IBD). He speaks at events with patients and professionals and is a member of the team that won the 2018 NIHR CLAHRC Northwest London Brian Turley Award for Patient and Carer Involvement and received a Highly Commended at the 2018 BMJ Awards.

My views are based on personal experience, that all patients, whatever their condition, have a unique aspect and special variation on their state of health. However, they also have rich experience of life, from all types of background—working and social environments—to be able to contribute significantly to the 'patient journey'.

There must be an effective partnership, for meaningful improvement, between all parties—the professionals (consultants, NHS staff, and academic liaisons) and patients, plus others within the health system.

Patients, particularly working adults, have limited time to contribute to the team work required to make the patient journey improvements truly effective. Special attention is needed to care for the physical and psychological situations in paediatrics and adolescents.

It has been said that much information is incomprehensible or badly-written, so health literacy is an important factor in improving communication. Much is complex for the public to understand readily, but the intelligence of the ordinary person must not be underestimated either—a happy medium must be found.

However, the initiative lies with the NHS staff. There has to be a leadership team who have defined roles, and who communicate with each other as well as with patients. Constant evaluation is necessary at all stages of the journey.

All this is just words, I know. What is tangible for me is that I've been an intrinsic part of the St Mark's Patient Centred IBD Care Model project over the last two years, to use 'Patient co-production to improve the quality of care and experience for IBD outpatients'. Our Patient Panel supplied two members, including yours truly. Dr Naila Arebi has been a great leader, with Dr Rishi Forfaria and other participants, including academic analysts and a local GP.

It has been salutary that we patients have been treated as equals, and been an integral part of the project. So all involved have learned so much, and will continue to learn and strive for improvement in the patient pathway. I have enjoyed thoroughly liaising with so many wonderful people for such a major scheme. Patient involvement, in all its forms, is here to stay!

Learning: Richard M Ballerand

Richard has a background in finance and military service and is an experienced strategic contributor. His reflections amplify the personal learning required and acquired through challenging personal circumstances and new opportunities.

My personal journey has been an interesting one. Until the late nineties, I had parallel military and civilian career paths. However, sustaining a Traumatic Brain Injury and other injuries after being run-over by a hit-and-run driver, I did not submit my doctoral thesis in psychology and resigned my commission as a reserve military liaison officer. I underwent years of rehabilitation, surgeries, and medication, managing to regain much of what I had lost. This necessitated my working part-time, leading to my involvement as trustee in several think-tanks and charities over the following fifteen years. From 2013 I often acted as carer and/or care-coordinator with my and my partner's ageing parents—two of whom had dementia with multiple co-morbidities—becoming increasingly involved with the British, French, and American healthcare systems.

I met Dr Rowan Myron on a Lay Partner course. She suggested I apply for an Improvement Leader Fellowship at NIHR CLAHRC Northwest London. I did so, was interviewed via *Skype from the US, and was accepted for the 2017–18 cohort. That was to be a challenging year, flying back and forth to the US, staying several months dealing with a parent's complex issues. Fortunately work could be done remotely, making use of NIHR CLAHRC Northwest London's excellent QI4U eLearning modules, with early morning Skype and telephone meetings. All staff were very helpful, particularly my mentor, Dr Catherine French, and our clinical lead, Dr Paul Sullivan.*

This led to several lay expert appointments; for example, NHS England's London Clinical Senate, NIHR's Health Technology Assessment committee, and NICE's Technology Appraisal Committee. I act as Central Commissioning Facility (CCF) public reviewer, BMJ patient reviewer, and serve on NHS trust advisory bodies.

What motivates me is being able to work with passionate people to achieve something beneficial for the wider community: helping in a small way to bring about positive change within our NHS. In the past, I had worked in extremely competitive sectors and found it refreshing to work with cooperative groups—which can be more productive as well as more virtuous. During my fellowship, I was able to learn from inspirational staff and fellows—including another patient fellow and nine clinical fellows. I joined the NIHR CLAHRC Northwest London Exchange Network led by Rachel Matthews and participated in its inspiringly collaborative away-days where I explored issues with stimulating individuals from a range of clinical, patient, and managerial backgrounds—learning that vulnerability provides the opportunity to grow and bring about both personal and organizational transformation. The programme is superbly facilitated and well supported.

> *I wholeheartedly recommend that people become more involved at all levels (NIHR CLAHRC Northwest London is excellent at advancing this) and engage in the ongoing process of gradual but iterative improvement. The improvement journey can be frustrating at times. However, with gradually implemented, measurable changes, and recursive feedback, I believe that it is definitely the best way to move forward.*

Systems Thinking

In this section, we summarize the contributions of three people who are associated with NIHR CLAHRC Northwest London from early on. Their input is valued because they work with the 'complex inter-relationships, connections and dependencies' (Lucas and Nacer 2015) and are able to see beyond isolated components of the health system.

Ron Grant with Dionne Matthew

Ron is an improvement leader fellow who promotes health at his local hospital. Ron developed influential connections at national level through this work. He was instrumental in promoting community engagement for a project focused on improving the awareness of atrial fibrillation (irregular heartbeat) as a cause of stroke and to encourage people to be screened.

> *We provide information for heart patients. We formed what we call a Cardiovascular Alliance which is heart, stroke, and diabetes. We are giving out information, reassuring some of the patients, especially those who have had some kind of procedure done or are about to have a procedure. We talk about healthy lifestyle, the kind of diet that they should be on, what changes in their diet they can make to improve their health, exercise, that kind of thing. All our volunteers get trained as health champions, they can go on any other courses they want, like the Expert Patient course.*
>
> *As the CEO of the Cardiovascular Alliance and the Upbeat Heart Help desk, I suppose I'm the one that monitors everything, I keep all the accounts, do a lot of the work myself for the group. I'm a member of the Clinical Cardiovascular Network in Hounslow (Borough of London) which with clini-*

> *cians, consultants, and general practitioners. We have raised issues, for example, the patient's right to say no to certain medication and if I take responsibility for saying I'm not going to take a particular medication then that's my choice, I shouldn't be forced by a clinician or consultant, and they found it difficult that there could be a comeback on them. I have been on BBC Radio discussing heart health and in a film about the AliveCor device (for checking heart rate) and its use.*
>
> *We are appreciated for what we do and the way we go about doing it. We have credibility and that is something that I am very hot on, you've got to be credible, you've got to be professional because at the end of the day that comes back to me.*

Maurice Hoffman with Rachel Matthews

Maurice Hoffman is a lay adviser in the Early Years Theme steering group at NIHR CLAHRC Northwest London. With a professional background in research, Maurice brings wide experience of working across different public service organizations. He worked in local government initiating and conducting social and population research. He became an Office for Standards in Education (OFSTED) Lay Inspector then retrained as a secondary school teacher of Health and Social Care and Business. In 2008, Maurice was appointed to NHS National Research Ethics Service (Brent) reviewing over 500 applications in ten years. Maurice supports the Patient Research Forum at his local NHS trust. He has experience and insight into health and care services from commissioning and delivery through to monitoring, as well as the research process.

> *I get involved because I want a continually improving world-class NHS. I enjoy learning new things and generating ideas. I like to make a difference and to be recognised for the contributions I make. I attend many conferences networking with participants, receive downloads from organizations and follow up interesting news. I keep myself up to date.*
>
> *I value my relationship with the team and the wider community at NIHR CLAHRC Northwest London because they are welcoming to new people. There are regular free opportunities to meet with clinicians, researchers, managers and other service users where we learn together. I receive and contribute to peer support through the Exchange Network.*

> *Through my association with NIHR CLAHRC Northwest London I've seen at first hand that it is fully recognised that improving healthcare in a practical way can only be done with the active involvement of patients and the community at every stage of every project. I believe that NIHR CLAHRC Northwest London has shown through its work, ethos and achievements to be an effective, responsive, creative, and caring organization.*

Fran Husson with Susan Barber

Fran contributed to several health service improvement projects to enhance patient safety by improving methods and incidence of medication reviews for patients who are prescribed a high number of medicines, with associated risks of adverse drug reactions and preventable hospital admissions.

Fran's involvement in service improvement projects took the form of regular participation in project team meetings working closely with pharmacists and using quality improvement methods, for example, process mapping and Plan-Do-Study-Act cycles. Achievements include improved uptake of reviews and avoidance of unsafe medicines practices in hospitals in Northwest London.

Fran was an influential member of a team of patients and healthcare professionals that developed a hand-held passport size booklet, My Medication Passport (MMP) (Barber et al. 2014; Jubraj and Blair 2015). MMP acts as an aide memoire and supports communication between patients, carers, and healthcare professionals about medicines taken; medicines changed; reasons for changes; other information such as allergies; use of medical aides; record of medical appointments; and special needs.

Fran has become an active agent in her own healthcare and an expert in the potential for the improvement of supported self-care. One example is her interest in and being an advocate for digital tools, such as the Personal Health Record (PHR), enabling active partnership between healthcare professionals and patients to manage treatment and monitoring of long-term conditions.

Fran was winner of the prestigious 'Inspirational Partner Award for Societal Engagement' 2018, for individuals or teams outside Imperial

College London who have made outstanding contributions for her work with the Health Protection Research Unit (HPRU).

Conclusion

Patients, carers, and service users are essential to the transformation of care. In addition to their interaction with health services, they bring unique stories shaped through life experience. The effective practice of patient and public involvement is necessary to the provision of future healthcare. It needs conditions which provide space and time for people to learn and lead together. Transformation of care and health organizations relies on a compelling strategic vision *and* leaders willing and able to support patients and professionals to work closely together.

Our experience of working together enriched the transformation and improvement opportunities in our applied health research programme. The shared emergent and experiential learning enabled us to evolve abstract ideas, translate policy rhetoric into real work, and move away from tokenism. Transformation requires us to embrace the possibilities of inclusive partnership. Advances in science and technology have delivered many benefits in terms of diagnosis and treatment. New developments must recognize and harness the collective intelligence generated through effective connections. We encourage and promote dialogue and practice to embrace the learning that lies ahead. Involvement is, and should be, dynamic, mutually informative, and enlightening. As Cherelle reminds us, ‘It’s your job, but this is my life’.

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