



Working outside the box – why patient and carer expertise matters for healthcare improvement and how it can be better utilised

This discussion paper is based on insights and reflections shared by members of the Patient and Carer Network (PCN) of the Royal College of Physicians¹

The PCN has been engaged in a range of successful improvement projects with the RCP and other agencies for many years. The recommendations outlined below are based on PCN members’ experiences of when they judge that patient involvement has worked best. Everyone working in healthcare improvement should include patient and carer perspectives in their activities, for both practical and ethical reasons.

We should also consider how patients and carers can make broader and more substantial contributions. PCN members are knowledgeable and realistic about the very considerable pressures that health services are under and the challenges of effectively utilising patient and carer expertise and building system capacity in this area. However, patients and carers represent a substantial reservoir of constructive insight, which is not currently being put to good use.

and policy, including in quality improvement. The idea that services can learn from patients and carers is now widely accepted and promoted and is reflected in many initiatives. This provides a strong platform to build upon.

Although the principle of inclusion is established, neither the range of the potential contributions nor the challenges of harnessing those contributions are as well understood. Here we offer a reminder of why patient and carer expertise matters and highlight the kind of contributions it makes possible – and some of the building blocks that are needed to help enable those contributions. Patient and carer involvement need not, and should not, be kept in a box labelled ‘lived experience’ – yes, patients and carers do bring knowledge of their personal experiences and preferences, and this knowledge is invaluable. But there are also good reasons to think and work outside this box.

improvement idea – however otherwise well informed and intended – is only a partial idea. Why is this? Firstly, services must take into account the perspective of their users if they are to work effectively. Patients and carers can be seen in some ways as ‘recipients’ of services; their needs, interests and perspectives should be treated as central in the same way as ‘clients’, ‘consumers’ or ‘users’ of any other services. However, this is a passive framing and an incomplete answer. Rather patients and carers should be seen as critically important sets of healthcare actors. The vast majority of the time, health and illness conditions and experiences are lived, managed and supported at some distance from clinical settings and healthcare professionals. It might be said that the work of patient self-management, peer support and family and voluntary caring is the real ‘frontline’ of healthcare. That is the core reason why it is crucial that health services are ‘joined up’, not only with one another, but with people’s lives. Healthcare improvement needs to help build that ‘joined up’ practice and itself be an example of it by being based on partnership working between professional and ‘lay’ healthcare actors.

Expanding inclusion

Over the past 20 years, there has been a major change in expectations about the inclusion of patients and carers in healthcare decision-making

Why does this matter?

No idea for improving healthcare is complete unless it is informed by patient and carers. Unless that condition is met then an

¹ Based on recorded conversations some PCN members with a successful track record a successful track record of contributing to quality improvement (QI), having also been members of a PCN QI group. Contributors include Alan Cribb, Alice Joy, Cuthbert Regan, Lynne Quinney, Peter Rees and Ray Jones. Thanks are due to Wellcome Trust for support, including for the costs of conversation transcription (Grant number 209811/Z/17/Z).

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Without a joined up approach, health services will remain disconnected from people's lives in a range of ways – providing 'solutions' that can be experienced as impracticable and inaccessible, leaving people feeling isolated, alienated and unsupported and failing to effectively harness the substantial resources and capabilities that individuals and communities can bring. In order for health services to be fit for purpose, they must be fit for the people who use them. Sometimes this concern to link professional and lay communities together results in call for greater 'health literacy' on the part of populations. This makes sense. But we should equally be asking for health systems to develop what might be called 'lives literacy' – to take a conscientious approach to learning about the experiences, perceptions and expertise of patients and carers.

What do patients and carers bring?

It is essential to recognise that patients and carers do not only bring their care experiences to the table, but a very wide range of diverse insights and capabilities. This diversity stems from different identities, histories and perspectives, different kinds of knowledge, interests and improvement agendas. Patients and carers can make contributions at

every level, from 'micro' to 'macro' – from improving specific practices and settings to strategic interventions in the design and organisation of services. The kinds of contributions include:

Sharing experiences of illness and healthcare – if services are going to be 'fit for purpose' they need to seriously consider what it feels like to be in need of, and subject to, healthcare and other services. This is why emphasis is sometimes placed on 'lived experience' informing healthcare improvement. This includes a whole gamut of considerations – practical issues including transport links and the scheduling of appointments, information needs and support for shared decision-making, and emotional agendas such as managing sometimes overwhelming feelings of vulnerability and uncertainty. Health professionals often report not fully understanding many of these things until they find themselves in the situation of service users. People who engage with services have a distinctive and invaluable vantage point, which is lacking in others. It is not merely that they see services from the 'user' end, but they often have pressing reasons to attend to what happens in detail and they are frequently in a position to 'see across' a range of organisations in their care trajectory

and understand how well different services communicate and work effectively together.

Advocating for person-centred service improvement – very many patients and carers can provide substantial insight into the strengths and weakness of provision and some of them develop exceptional capabilities to communicate their experience and vantage point in important and compelling ways. Many other patient and carer representatives are highly skilled at eliciting and sharing insights relevant to improvement. Hence expertise into advocating for, and formulating, needed service change and improvement may come in different forms. Some patients and carers may base contributions on vivid accounts of their own experiences and observations. Others may present accounts based on consolidating a range of experiences together (often based on consultation and deliberation with peers). At the very least, patient and carer representatives will ensure that the distinctive vantage points of patients and carers are 'on the agenda' when improvements are discussed.

Acting as partners and colleagues in planning, policy initiatives and projects – patients and carers should not only be regarded as useful sources of 'experiences' or as data sources to inform improvement. Insights from, and crucially the agency of patients and carers can become embedded in improvement practices when they are included as colleagues and collaborators in specific initiatives and projects or broader strategic action. The more patients and carers are actively engaged at every stage, ie in designing, enacting and evaluating improvements, the more fully their

² One influential approach to healthcare improvement based on coproduction is Experience-based Co-design (see, for example, The Experience-based Co-design toolkit at <https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>)

capabilities can be harnessed. This not only means patients and carers are being treated with appropriate respect, but it substantially decreases the chance that initiatives will be disconnected from what matters to people, effectively being ‘improvements’ in name only. Approaches to improvement that are based on partnership working and deliberately deploying the perspectives and agency of patients and carers are sometimes described as ‘coproduction’.²

Strengthening organisational and professional knowhow – just as health professionals are not ‘one dimensional’ neither are patients and carers. When working on improvement-related activities, they can draw upon the whole of their life experiences, including their work experience. For example, within the PCN, colleagues have substantial professional experience of working within and for diverse multicultural organisations and communities, in science and technology, public service delivery, legal regulations and advocacy, the management and leadership of change in various sectors including the health sector, and even working directly on NHS quality improvement. These forms

of organisational and professional knowhow can strengthen the critical and practical capacity of the teams they join and help them better represent patient and carer vantage points.

Providing leadership in health systems and institutions – as is well-established, health systems are not wholly run and led by professional groups. There are clear-cut examples here, for example, where individuals, chosen partly because they represent patient and carers perspectives, take positions on – and sometimes chair – committees and boards of institutions and professional organisations. There are no obvious limits to leadership here, especially in an era where the importance of ‘distributed leadership’ is understood – ie where leadership and support for change can come from multiple directions and levels within services. Furthermore, a good case can be made for saying that more leadership roles should be created, or opened up, within health systems precisely to ensure that the insights, knowhow and accumulated wisdom that derive from being embedded in patient and carer experiences are harnessed and applied at senior levels.³

Working collectively for system and policy development or reform – healthcare improvements may require policy changes with regard to funding, workforce and system re-design. Patients and carers working in groups, and working in partnership with professionals and other agencies, can help to advocate and lobby for the required change. Many patient and carer representatives often feel passionately about service provision – sometimes fuelled by experiences of poor provision they would like to see changed, sometimes fuelled by ‘gold standard’ experiences that they would like to see shared more widely. These commitments can make them highly credible and powerful allies for system leaders wanting to make improvements.

How can we use, and not waste, patient and carer expertise?

It is clear that patients and carers have a great deal to offer. We are moving in broadly the right direction as far as inclusion in improvement is concerned, but progress is often both slow and partial. It is wise to steer away from blame here, but rather to acknowledge

Box 1. How to use patient and carer expertise.

Sustained motivation and resourcing	It is important to avoid superficial ‘tick box’ inclusion.
Inclusion across a full project trajectory	Patient and carer participation is valuable, from agenda setting to outcome evaluation.
Dissolving barriers	Communication is key. Avoid jargon and unnecessary acronyms.
Supporting partners	The contributions of some patient and carers will benefit from support from one another and from other colleagues.
Thinking about skill mix	Patients and carers bring very different kinds of knowledge and experience. Consider the combinations of insights and expertise needed from case to case.
Evaluate	Ask about the costs and benefits for everyone involved.

³ The pioneering work of David Gilbert in articulating and championing this agenda is particularly notable. (See, for example, *The Patient Revolution* (2020), Jessica Kingsley Publishers, London.)

Clearly the use of patient and carer expertise is neither easy nor a panacea. It entails challenges and complexities and there are potential risks and costs to consider both for patients and carers and for health systems.

that properly utilising patient and carer expertise is challenging. Good intentions are not enough; concerted and sustained action is required in order to translate aspirations into practical action. An important first step is to take this ‘translation’ challenge seriously and to explicitly ask about the building blocks that have to be put in place. Organisations should ask: How do we normally aspire to support, develop and respect our colleagues, and are we applying the same principles here? Some key building blocks are summarised in Box 1 and discussed below.

Sustained motivation, resourcing and capacity building from service providers – While the principle of including patients and carers in improvement processes is widely accepted and espoused, ‘inclusion’ sometimes only takes place in a superficial way (a culture of ‘box ticking’). Even when well-intended, this can be experienced as marginalising, or even patronising, by patients and carers. Indeed, this situation often comes if careful thought has not been given on how to best to facilitate the contributions – and enable the agency of – patients and carers.

Inclusion across the full trajectory of an initiative or project – In order for patient and carer expertise to be used effectively, their input must be included at every stage of an improvement process – including agenda setting or problem definition,

design and roll out of interventions and evaluation. When patient and carers are just ‘consulted’ at one stage, their capabilities are not being fully drawn upon and they may not be being treated with due respect. For example, it is unacceptable for patients and carers to be included in a project, but then not informed about project developments or outcomes. Wherever possible, those involved in projects should have an account of some ‘tangible’ goal.

Attention to communication barriers – Wherever there is partnership working between professionals and lay colleagues, there is a need to attend to communication barriers, including unpacking jargon and acronyms. More broadly, there is a risk that other inadvertent ‘professional tribe’ behaviours – insider styles, expectations and ways of relating – get in the way. It is accepted that professionals have to manage time and resource constraints that limits their availability and accessibility, but even a little conscious attention to dissolving these potential boundaries can make a substantial difference.

Supporting interested patients and carers – Not all patients and carers will be interested in contributing to healthcare improvement, and among those who are there will inevitably be varying degrees of experience, confidence and expertise. In these circumstances patients and carers

can work together in groups and help facilitate one another’s participation. In addition, mentoring and training arrangements can be put in place to enable what may sometimes be neglected but crucial contributions, eg from people managing vulnerabilities, with marginalised identities or facing other challenges. Everyone working on improvement initiatives can themselves contribute to these supportive arrangements.

Being mindful of patient and carer ‘skill mix’ – As summarised above, patient and carers may bring very different kinds of contribution. An organisation interested on drawing on their expertise should devote some time to thinking about what combinations of people they might call upon, how best to identify them, what it is realistic to expect from them, how relevant expertise may grow over time and how roles and contributions may evolve. It is often important, for example, to encourage participation from someone to share ‘lived experience’ of a service. However, even an individual volunteering and selected largely for that reason may also be looking for opportunities to exercise meaningful agency and leadership in improvement projects.

Building evaluation in – Clearly the use of patient and carer expertise is neither easy nor a panacea. It entails challenges and complexities and there are potential risks and costs to consider both for patients and carers and for health systems. We always need to be ready to ask hard questions about both costs and benefits. But this is not a reason to be negative. It is simply a reason to treat related initiatives like any other responsible health service developments, eg ensuring lines of responsibility and accountability are discussed and clear, and conducting systematic evaluations of approaches and sets of initiatives. ■