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Service user engagement in quality improvement: Applying the National Involvement Standards

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Service user engagement in quality improvement: Applying the National Involvement Standards

Abstract

Purpose

National and local policy supports the involvement of patients at all levels in the design, delivery and improvement of health services. Whilst existing approaches to support involvement have been described and disseminated, including the 4Pi National Involvement Standards, their application in quality improvement is rarely reported.

Approach

A quality improvement initiative within a mental health trust was developed with a multi-disciplinary team, including those with professional experience of delivering or improving care and those with lived experience. The aim of the initiative was to improve the physical health of inpatients within an acute mental health unit. This case study aims to describe how the integration of concepts from the 4Pi National Involvement Standards (Principles, Purpose, Presence, Process and Impact) provided a framework for engaging and involving service users. The case study also aims to describe how co-design was included within the 4Pi approach and supported the development of a tool to aid improving physical healthcare.

Findings

The 4Pi National Involvement Standards provided a guiding framework for the involvement of service users within a quality improvement initiative. Value of the approach was realised through the co-design of a tool developed by service users, along with healthcare professionals, to facilitate discussion and support shared-decision making about inpatients' physical health.

Practical implications

Identifying 'ways that work' for service user involvement is crucial to move beyond the policy rhetoric or tokenistic involvement. Involvement in quality improvement initiatives can bring benefits both to services and the service users themselves.

Originality/value

Whilst the 4PI approach is recognised as a useful framework for involvement, few examples exist of its practical applications within a quality improvement setting.

Introduction

Service user involvement in quality improvement

People with serious mental illness (SMI), such as schizophrenia and bipolar disorder, have a significantly reduced life expectancy and a higher prevalence of physical health disorders than the general population (Bartels, 2015). Assessing the physical health of patients when they are in hospital offers an opportunity to identify risk factors for developing conditions such as cardiovascular disease and diabetes and provide advice and support on access to services on discharge. Unfortunately, patients with SMI are rarely offered this support when they are in specialist mental health hospitals, despite recommendations in numerous national guidelines (Health and Social Care Information Centre, 2013).

Many approaches have been developed and promoted for the involvement of patients and service users in their care and in the design, delivery and improvement of services and health related research. Despite the dissemination of such approaches to involvement, their application in quality improvement, especially related to the impact of involvement, has rarely been reported (Mockford, Staniszewska, Griffiths, *et al.*, 2012). Whilst there is no consensus on what defines 'involvement' the National Institute of Health Research (NIHR) suggest that involvement is carried out 'with' or 'by' patients and service users rather than 'to', 'about' or 'for' them (Hayes, Buckland & Tarpey, 2012). The 4Pi National Involvement Standards is one such framework that has been published to provide guidance for the involvement of patients, service users and carers (Faulkner, Crepaz-Keay, Kalathil, *et al.*, 2015). The 4PI framework was developed following consultation, research and review and outlines a good practice framework for achieving involvement. The 4Pi standards comprise of five key concepts essential for achieving meaningful involvement: *principles, purpose, presence, process* and *impact,* summarised in Table 1.

Table 1: 4Pi concept definitions operationalised for a quality improvement initiative (Faulkner, Crepaz-Keay, Kalathil, *et al.*, 2015)

4PI Concepts	Operationalised definitions
Principles	Clear and shared principles and values
Purpose	Agreed purpose of involvement linked to the improvement of services and service user/patient experience
Presence	Involvement of service users at all levels and stages of an initiative
Process	Communication and support to ensure engagement with patients and the public
Impact	Assessment of the effect of involvement on both the individuals and the initiative

Establishing a quality improvement team - setting the tone for involvement

Healthcare professionals from an inpatient mental health service in northwest London identified the case for improving the physical health of patients admitted to their unit. In order to achieve meaningful and lasting change it was recognised that a multi-professional, representative team needed to be created and a quality improvement approach should be employed to allow the team to develop and test local solutions. The NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Northwest London supported the teams to use a range of quality improvement tools between September 2014 and March 2016 and facilitated the service user involvement.

The 4Pi framework, explicitly adopted by the quality improvement team, provides guiding *principles* for involving service users in quality improvement initiatives. The framework informed the development of a plain English "involvement proposal" and "role descriptions" for service users setting the tone for early discussion with, and recruitment of, service users into the quality improvement team. The involvement proposal and role description together addressed each of the 4Pi concepts. *Principles* were described in detail, with clear commitments made to adhere to and work within them throughout the initiative. A section on why the initiative was seeking the involvement of service users addressed the *purpose*, emphasising why it was important to have all possible experiences, skills and knowledge available to ensure the work was relevant to the everyday experience of service users. The involvement proposal also detailed the benefits not only for the quality improvement initiative but also for those involved, offering in return for their time and expertise wider opportunities for training in quality improvement skills, research and personal learning and development within CLAHRC Northwest London programme.

Details of the aims of the quality improvement initiative along with meeting schedules and details of responsibilities, expectations and time commitments for all team members were provided to ensure services users p*resence* and contribution were clear and well thought out. In this way, all members of the quality improvement team had sufficient information and assurance that the *processes* were accessible to services users, transparent and adaptable and designed to support effective and meaningful involvement. This was reinforced by a commitment to work together to identify and remove or reduce any unanticipated barriers to involvement services users may encounter.

The anticipated *impact* of involving service users as full and equal members of the quality improvement team were described and included achieving a more accurate understanding of service user experience by identifying groups and individuals not usually involved in this type of work to appreciate alternative explanations, interpretations, ideas and perspectives.

Delivering quality improvement - engaging service users in the process

Following the recruitment of three service users to the quality improvement team a wider range of additional stakeholders, including ward staff and staff from community mental health services, were invited to join. Subsequently it was necessary to develop a shared aim to ensure consensus that not only met the needs of the stakeholders but was also within the scope of what could be achieved. This was facilitated with the use of a quality improvement approach developed by CLAHRC Northwest London called "the action effect method" (Reed, McNicholas, Woodcock, *et al.*, 2014). The method involves unpacking the initial aim of the initiative to understand what activities could be undertaken to achieve this and then checking assumptions about the causal links and relationships between these. This provided an opportunity for the whole quality improvement team, including the service users, to be actively involved in shaping the aims of the initiative and defining the shared *principles* and values of the team. The *impact* of having service users fully involved in the action effect method was that it led to a greater emphasis placed on the importance of informing and empowering patients about their own physical health needs. This led directly to the identification by the service users that an intervention or tool was required that could facilitate shared-decision making between healthcare professionals and patients about their physical health. Consequently, service users and healthcare professionals worked to co-design an appropriate product. It was anticipated that using co-design approach would ensure that the tool would be more acceptable to both healthcare professionals and patients.

The *presence* of service users was not only at the level of the project steering committee as advisors, but also working directly with healthcare professionals to develop the intervention as part of an open and accessible *process*. The service users also took the opportunity to engage with inpatients within the unit to discuss issues about their physical health and assess their interest in the development of a tool to support decisions about their physical healthcare.

Furthermore, the service users were ideally placed to use their existing networks and contacts to promote discussion about physical health and gather feedback from peers on the acceptability of such an intervention. This intelligence was combined with a review of existing materials and with the expertise of healthcare professionals in the co-design of an individualised patient held physical health plan. The plan was iteratively developed as a tool for not only recording patients' physical health but also to facilitate discussion about their physical health needs and support shared decision making about referral to appropriate interventions/services. The importance of using a quality improvement approach such as plan-do-study-act (PDSA) cycles was crucial in ensuring the tool was fit for purpose and provided multiple opportunities for staff and service users to feed in to its development (Langley, Nolan, Nolan, *et al.*, 2009).

Developing interventions – working with service users

In order to support the development of the intervention and support the service users directly, supplementary meetings and workshops were scheduled, in addition to the monthly project board meetings, chaired by the clinical lead. Progress with the development of the intervention was reported back at the project board level to ensure that this was communicated with the whole quality improvement team and feedback gathered as part of the PDSA cycles. Ensuring *processes* were established for decision-making and communicating were fundamental project management tasks that were necessary to create a dialogue between individual stakeholders, including the service users, emphasising the need for robust *processes* that support involvement, especially for those 'outside' the organisation. An important aspect of creating this *process* was that it benefitted the whole team, not just the service users. Whilst ensuring that meetings were accessible (e.g. deconstructing jargon and technical processes) so that all team members could participate was difficult, this did help remove hierarchies and allow for a generally "flatter" feel within the quality improvement initiative. Of course, problems did arise that needed to be dealt with, for example service users found their access to certain areas restricted, as they were not provided with organisational identity badges, despite being official members of the team. This was somewhat resolved by providing name badges specifically for service users involved in the initiative but didn't really address this at an organisational level.

Assessing impact and sharing knowledge – a role for service users?

The *impact* of service user involvement could be seen directly by the co-design of the patient held booklet: 'My physical health record explained'. Key features of the booklet that was developed included: the fact it was patient held; it recorded patients' key physical health indicators including blood pressure, body mass index, waist circumferences, alcohol consumption etc; contained individualised rating of these physical health indicators to flag up risk factors and included a numerical risk of experiencing a cardio-vascular event such as a heart attack or stroke. Lastly, the booklet also contained bespoke advice about interventions and local services that the patient could access on discharge from hospital that could help support them to reduce their specific risk factors for developing cardio-vascular disease. In addition to the impact service user involvement had on the quality improvement initiative, the impact on the service users themselves was equally important. Service users reported that: "…as a service user I felt that being involved in the project has given me more confidence to work with professionals, and the project itself has helped me understand my own continuous battle with my physical health"; also "… I've been involved in many projects over the years, but this is the first time I've really felt part of a team."

In addition to service users, staff expressed the impact the project and the new way of working had on their role: "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." Furthermore: "The integration of people with lived experience as equal members of the project team from the outset was incredibly important for the success of this project, as it incorporated the experience and perspective of the "end-user" of the intervention in a way that would not be possible otherwise. The fact that these team members led on the patient-held booklet means that it is unique and innovative. I feel that we have a much higher chance of enabling our patients with SMI to self-manage their long-term physical conditions in the light of this work. This feels like far more effective service user involvement than the addition of a "representative" to a meeting or project group, which risks feeling tokenistic".

Moving away from the impact of service user involvement on members of the team, the impact of the quality improvement initiative on the delivery of services and patients outcomes remains an important issue, and despite an array of methodological challenges, is still an expectation (Øvretveit, Bate, Cleary, *et al.*, 2002). Whilst there are formalised research methods for process, outcome and impact evaluations, the resources and time often required from this rigorous evaluation isn't often available (Rossi, Lipsey & Freeman, 2003). Whilst process evaluation, to some degree, is embedded within the quality improvement approach, through the monitoring of physical healthcare assessment, working with service users to evaluate the outcomes and impacts of the initiative offer a new opportunity. Although relatively unexplored, the idea of service user evaluation is not new (Thornicroft & Tansella, 2005). Current plans for evaluating the initiative include supporting one of the service user team member to conduct a survey and/or interview patients that have received the new service. The focus would be on generating a better understanding of some of the local challenges to delivering this service from the patients' perspective and identify areas where it might be possible to demonstrate a direct impact of the project on changes to lifestyle behaviours. Furthermore, the role of service users in promoting and disseminating the initiative was valued greatly, with service users working with other members of the team to discuss the importance of the

initiative at various boards and committees within the organisation but also at external events and meetings. The active role of team members with lived experience had benefits well beyond improving outputs from the initiative. For some staff working on the initiative, this was their first experience of working so directly with people who had themselves formerly been users of services, and the impact of this was noticeable as relationships were built and assumptions about professional and patient roles were replaced by more collaborative working relationships.

Lessons learned

The reporting of user involvement in quality improvement initiatives is essential to not only share good practice but to disseminate lessons about what works and what doesn't, but this has to be understood in the context of quality improvement (Esmail, Moore & Rein, 2015). Fortunately, this example of a quality improvement initiative was provided with the resources, in terms of training for quality improvement and user involvement, and financial resources and commitment to support the clinical team. Whilst these are prerequisites for successful engagement the presence of an organisational culture, as in many mental health services, that supports engagement of service users and quality improvement approaches, was also important. Beyond these contextual factors, a number of lessons can be drawn from this case study that can hopefully support future initiatives to engage more fully with service user involvement.

- Combining the 4Pi involvement standards with a systematic approach to quality improvement, such as that developed by NIHR CLAHRC Northwest London, can provide a mechanisms to introduce changes in clinical care and facilitate the involvement of patients/service users;

- 4Pi inclusion standards offer a useable framework through which patients/service users can be involved at different levels, according to the needs of the organisation/initiative;

- Recruiting people who are able to bring relevant experience, be that lived experience or professional experience and other life skills, enable them to contribute to the initiative in a meaningful way;

- Making an effort to ensure that meetings remained accessible for all team members so they can actively participate can be difficult but can remove hierarchies within a quality improvement initiative;

- Organisational issues/policies can create barriers to the inclusion and full participation of service users and should be identified and dealt with;

- Demonstrating the benefits of working with service users at an organisational and clinical level is necessary to ensure the buy-in of senior leaders and healthcare professionals.

Conclusion

Whilst examples of service user involvement in research that aims to improve the physical health of those with SMI exist, this study offer a pragmatic approach to service user engagement in quality improvement (Gray, Larsen & Faulkner, 2013). A number of key challenges were identified throughout the development of the initiative, with a particular focus on inclusivity of all team members to ensure effective team functioning and the utilisation of skills within the team. Engagement of ward staff including junior doctors and nursing staff was essential to provide opportunities for them to supply feedback for the project board, but also feedback directly from inpatients, gathered by the service users, was equally important. Engaging with both staff and patients, through the service users, provided opportunities to present key benefits of the initiative at both the clinical and organisational level. This highlights the level at which this initiative was able to align the process of involvement and quality improvement to some of the factors identified for successful involvement, including the ability to develop non-hierarchical, multidisciplinary collaborations and a commitment to rapid action and reflection provided by a quality improvement approach (Renedo, Marston, Spyridonidis, *et al.*, 2015). Furthermore, despite successful involvement of service users, this is no guarantee of achieving successful and sustainable improvement in care processes or clinical outcomes; but further integration of service users into the continual review and improvement of services offer opportunities for continuous improvement. Whilst there is recognition of the challenges of user involvement in quality improvement initiatives, integrating quality improvement methods with the 4Pi approach offers a structure by which meaningful engagement can be achieved and the benefits of involvement realised for both staff and service users.

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