

Developing a 'critical' approach to patient and public involvement in patient safety in the NHS: learning lessons from other parts of the public sector?

Josephine E. Ocloo BSc MSc PhD and Naomi J. Fulop BSc MPH PhD

NIHR King's Patient Safety and Service Quality Research Centre, King's College London, Strand, London, UK

Abstract

Correspondence

Josephine Ocloo
NIHR King's Patient Safety and
Service Quality Research Centre
King's College London
2 Basement
Strand Bridge House
138-142 Strand
London WC2R 1HH
UK
E-mail: josephine.ocloo@kcl.ac.uk

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There has been considerable momentum within the NHS over the last 10 years to develop greater patient and public involvement (PPI). This commitment has been reflected in numerous policy initiatives. In patient safety, the drive to increase involvement has increasingly been seen as an important way of building a safety culture. Evidence suggests, however, that progress has been slow and even more variable than in health care generally. Given this context, the paper analyses some of the key underlying drivers for involvement in the wider context of health and social care and makes some suggestions on what lessons can be learned for developing the PPI agenda in patient safety. To develop PPI further, it is argued that a greater understanding is needed of the contested nature of involvement in patient safety and how this has similarities to the emergence of user involvement in other parts of the public services. This understanding has led to the development of a range of critical theories to guide involvement that also make more explicit the underlying factors that support and hinder involvement processes, often related to power inequities and control. Achieving greater PPI in patient safety is therefore seen to require a more critical framework for understanding processes of involvement that can also help guide and evaluate involvement practices.

Introduction

The late 1990s marked a distinct shift in the approach to user involvement in health care emphasizing the importance of patient and public involvement (PPI) as part of Labour's NHS 'modernization' agenda. The PPI agenda was given greater momentum by evidence of serious clinical and service failings in health, highlighted by high-profile inquiries (Bristol,¹ Shipman,² Alder Hey,³ Maidstone and Tunbridge Wells,⁴ Mid Staffordshire NHS Founda-

tion Trust),⁵ frequently fought for by patients and their families, harmed by patient safety incidents. These investigations have stressed the role of PPI as a way of delivering safer individual care and improving the performance and accountability of health services, through a shift away from paternalism^{1,5} to patient empowerment.⁶

These events have led to an array of initiatives on PPI in health⁷⁻¹⁰ and a legal duty to involve through the NHS Act 2006.¹¹ This has been aimed at improving the quality of individual

care and making changes to improve the performance of wider systems and services. More recent attempts to embed PPI across NHS services have seen *World class commissioning*,¹² Darzi's *High quality care for all*,¹³ the *NHS Constitution*¹⁴ and the White Paper *Equity and excellence*,¹⁵ all reflect the shift of involvement to the forefront of the policy agenda. In patient safety, key documents^{16–18} have also set out clear expectations for NHS trusts to develop PPI in all initiatives to support a patient safety culture change within the NHS.

Yet despite this considerable momentum to involve patients and the public, there is little evidence that involvement is a mainstream activity that sits alongside other policy and performance requirements in the NHS.^{11,19} In the context of patient safety, evidence suggests that trying to achieve PPI has been even more difficult than in mainstream health care.

Ten years after the Bristol report identified the need to place PPI at the centre of developing a patient safety culture, a number of articles and reports suggest there has been a considerable lack of progress.^{4,6,20–23} Vincent and Coulter²⁰ maintain that at most stages of patient care, the potential exists for involvement and participation: for example, in reaching a diagnosis, making decisions on treatment, choosing an appropriate health provider, ensuring treatment is adhered to and monitored and ensuring the identification of adverse effects and taking action in response to this. This is seen as particularly important where there has been a breakdown of trust resulting from harm caused to patients.

Coulter and Ellins²¹ in a systematic review of the patient safety literature concur with this view, highlighting the potential for patients to contribute to safety in their individual care, preventing the occurrence of errors and contributing to service design and improvement.²¹ They report little evidence, however, that patients have been involved in the development of a patient safety movement since the Bristol Report was published in 2001. In developing involvement strategies further, they note that far more needs to be known about the ways that

safety improvement can be enhanced through patient involvement and 'subjected to formal evaluation so that best practice can be identified'.²¹

In exploring further how the PPI agenda could be developed in patient safety, this paper develops three main arguments. Firstly, there is a need for a wider and more nuanced debate about how to progress PPI in patient safety which goes beyond the mainly atheoretical nature of much of the literature on PPI in patient safety.²⁴ Secondly, this debate needs to recognize the contested nature of involvement and the way in which calls for greater participation across the public services have been driven by a range of disenfranchised social groups, challenging the nature of oppressive and discriminatory service provision, which has excluded them. Lastly, there is a need to consider what lessons can be learned for the development of PPI in patient safety, from this contested agenda and the development of a range of critical theories that have emerged more broadly in health and social care in the study of involvement processes.

Drawing on these arguments, some components are proposed for a framework to help guide and evaluate involvement. These are highlighted in the paper by looking at why it is important to understand the contested nature of involvement and why this context requires a more 'critical' approach to the issues and some key ingredients of an approach to involvement based upon patient and the public involvement as empowerment. These components are brought together in Table 1, which gives some examples of how these ideas can be developed in practice.

Understanding the contested nature of involvement

More broadly in the public services, the term 'service user' has come to describe a range of 'people on the receiving end of health, welfare and social care policies and services'.²⁵ These individuals and groups have used the term 'to challenge and change their shared experience of

Table 1 Learning lessons on user involvement: theory linked to practice – a framework to guide patient and public involvement

Recognizing history/ context of involvement →	Drawing on values/theories that address the contested nature of involvement →	Applying differentiated approaches to involvement →	Challenging barriers/ supporting the involvement process →
Emergence of social movements/self-help groups (e.g. BME, disabled, women's, lesbian and gay groups, harmed patients) that challenge the nature of oppressive/harmful service provision and professionally driven agendas	Drawing upon critical perspectives on involvement/participation (e.g. Black, anti-racist, feminist, social model of disability, anti-oppressive practice (AOP), consumerist/ democratic/empowerment theories) ↓	Involvement at the individual and collective level	An organizational commitment to support involvement/challenge power inequities and empower users
The emergence of user involvement across the public services	These challenge a dominant biomedical model of health and illness	Working with diverse groups of users within an AOP model that challenges oppressive practice/empowers individuals within their care/treatment and at a collective level	Identify clear opportunities for involvement and how lay members want to be involved
Compliance with policy/legal drivers for involvement	Highlight organisational factors about power and conflict that hinder/sup port involvement processes Draw on empowerment theories that challenge oppressive social structures/give voice to user led perspectives/approaches on change	Developing involvement in different types and levels of activities and in own treatment	Clarify for staff/lay members how involvement will take place and include/empower diverse/under- represented groups to be involved Specify how the involvement process will be supported/resourced e.g. time, information, training, expenses, advocacy

oppressive policies and provision'.²⁵ The term can therefore be understood as part of a much wider discourse that has emerged across the public services to explain the drivers for greater involvement in service delivery.

Cowden and Singh argue that during the late 1970s and throughout the 1980s, this discourse was driven by a number of campaigns and new social movements (Black, anti-racist, feminist, lesbian and gay and disability rights movements). These groups had diverse agendas in challenging discrimination and oppression and campaigning for social change.²⁶ Related developments also saw the emergence of a movement

of mental health service users active in deploying collective action to challenge traditional ways of thinking in mental health service provision and in wider society.²⁷ These activities have led to considerable attempts to involve service users in public services in the United Kingdom and in many other Western countries.²⁸

This debate has subsequently highlighted the way in which a diverse range of groups in society have been oppressed and disenfranchised and have struggled to achieve citizenship, welfare rights and access to services that genuinely meet their needs.^{26,29–32} As part of this debate, critiques have also pointed to a 'democratic deficit'

in society that has excluded the active participation of citizens in the planning of public services and decision making.^{33,34} This has raised questions about the need for new forms of participation and involvement to address this vacuum.³⁵

In health, this debate has seen various arguments emerge that criticize the limitations of a biomedical model of health and illness. They have also criticized the dominant role of professionals, citing their disabling effects in causing health-care iatrogenesis, leading in turn to a loss of public confidence in their expertise.^{36,37} These arguments have stressed the importance of recognizing that lay people have their own valid interpretations of health and illness that are essential to the process of treatment and health care. This situation is seen to require new types of relationships between patients and professionals that go beyond paternalism and which embrace more informed and shared models of treatment and decision making.^{27,38,39}

More specifically in patient safety, various high-profile investigations into clinical failures (mentioned earlier) suggest that imbalances in power between patients, health-care professionals and health-care organizations are a major cause for concern. Whilst there is little in the literature on the views of 'harmed patients' (i.e. patients and their families affected by a patient safety incident), evidence suggests that these patients have strong opinions about safety, accountability and changing the system.^{40,41} These experiences when viewed as part of the broader political and theoretical discourse that has driven involvement across the public sector suggest that the PPI agenda in patient safety can be seen as part of a new social movement to develop in health care.

This has implications for developing an involvement agenda given that health social movements have been described as providing 'collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organizations, supporters, networks of co-operation and media'.⁴² To broaden the debate on harm, Sharpe and Faden⁴³ have pointed to the need

for a broader knowledge framework for the evaluation of medical harm and the imposition of risk that is based upon a more patient centred ethos.⁴³

This paper argues that further development of PPI in patient safety must go beyond a largely atheoretical approach in order to understand and address concerns about how different groups experience service provision. Critical theories in health and social care (set out in the next section below), relating to power inequities in service provision and how these can be addressed, are considered to provide a useful way of contributing to a more critical framework to guide and evaluate involvement in patient safety.

Developing a more critical approach to involvement in patient safety

Recent events at Mid Staffordshire NHS Foundation Trust reinforce the idea that the empowerment of patients and the public and providing them with methods to support their engagement, particularly where they have concerns, is important in delivering high-quality and safe NHS care.⁶

In patient safety however, there has been little debate about how issues of power and empowerment may affect involvement processes and the experiences of different groups. Whilst the term service user is often used synonymously with PPI, the latter term is often a 'taken for granted' concept, which is used uncritically. This has meant there has been little understanding of the contested nature of involvement and the way in which the experiences of patients, the public and particularly harmed patients have driven the patient safety movement at a national and international level (WHO 2007).

We suggest that critical perspectives on user involvement in health, social work and social care can contribute to the development of a conceptual framework to guide involvement in patient safety in different ways. A starting point would be to recognize that a broader conceptual framework, underpinning involvement, needs to go beyond the clinical markers and individual

agency associated with a narrow medical model. It is argued that a biomedical approach tends to underpin an instrumentalist method-based approach to involvement that ignores the considerable power imbalances and health inequalities⁴⁴ that exist at the structural, organizational, individual and cultural level in health care, which adversely impact upon and exclude a range of different groups. In patient safety, Antonsen has identified the need for more research to address issues of power and conflict in organizations that to date have tended to rely mainly upon a 'harmony model of organizational life'.⁴⁵

In terms of PPI in patient safety, these power inequities are highlighted at the individual and collective level of care in different ways. Evidence, for example, shows that a 'knowledge and status imbalance' between patients and practitioners affects the ability of a patient to adopt safety-related behaviours.^{24,46,47} Research by Peat and Entwistle *et al.*²⁴ found that safety interventions which were most successful required patients and their representatives to be well informed and knowledgeable. This capacity was found to vary between individuals and to be significantly affected by educational level, income, cognitive skills and cultural differences, which might affect patients health beliefs and ability to utilize health services.²⁴

In addition, Peat *et al.* found that many patients were uncomfortable and unwilling to challenge health professionals' opinions and practice. At the collective strategic level, this power imbalance was reflected in the way that patient representatives were largely expected to work within existing systems in improving quality and safety. This was seen as problematic as it denied these individuals the space to redefine the issues and thus bring their own lay perspective 'to the development and improvement of services'.²⁴ This context clearly has implications for PPI, particularly given the identification of staff support and encouragement to patients as a key factor in the development of successful involvement practice.⁴⁶

We therefore argue that adopting a more critical approach to involvement will entail

going beyond current theories/models (e.g. Health Belief Model, Theory of Planned Behaviour) that have been extensively used to predict individual patient involvement in health. Instead, a broader framework is needed that recognizes the contested nature of involvement and the importance of including in debates about patient safety, alternative narratives from patients, their families and self-help groups. These narratives are important as they raise key issues about the medical and social processes that construct harm which challenge dominant perspectives on the issues (Ocloo 2010).

Empowering involvement practice in patient safety

Given this context, a more critical and differentiated approach to the development of involvement strategies needs to look at issues of power and empowerment in the involvement process. Some thinking in this area when developing involvement strategies at the collective rather than individual practitioner level has seen two distinct conceptual models or approaches (characterized as consumerist/managerialist and democratic) predominate since the 1990s.⁴⁸ These have been linked with influencing different types of user involvement in public sector organizations.⁴⁹

With the managerialist/consumerist approach, Beresford has argued that methods of involvement have been framed mainly in market research terms of 'improving the product' and through market testing and feedback, based upon data collection methods and consultation designed to improve service provision on the basis of consumer or customer intelligence.³¹ In contrast, the democratic/liberational approach emphasizes direct involvement of users in the decision-making process and broader democratization at a community level.⁴⁹ Beresford³¹ argues that this approach focuses on people having more say in organizations that impact upon them and on being able to exert more control over their lives.

In relation to different models of empowerment, Starkey,⁵⁰ drawing upon McLean's

work,⁵¹ has argued that a consumerist model of empowerment is likely to be less relevant in changing people's lives than a liberational model. This is because it focuses on people having to make choices within predetermined service systems defined by service providers and policy makers.⁵⁰ Within the democratic/liberationist approach, Starkey drawing upon Barnes⁵² notes that empowerment requires change to take place within individuals, as well as broader social systems and services, to support the participation of those previously excluded.⁵⁰

In practice, Tritter and McCallum²⁸ have attempted to broaden the theoretical debate about consumerist/managerialist approaches by defining PPI in more detail. They argue PPI covers a spectrum of activities related to treatment decision making, service evaluation, service development, education and training and research. These activities are considered to relate to different dimensions of involvement: direct and indirect; individual and collective; and proactive and reactive. This matrix takes into account the manner in which patients and the public are involved in decision making, whether participants are acting as sole individuals or part of a group, community or population, and whether participation is reactive in responding to a pre-existing agenda or proactive in shaping it.⁵³

The ideas above therefore provide a basis for a framework for empowering involvement practice in patient safety. These could also be further developed by drawing upon various critiques to emerge in social work in the 1970s. These critiques, related to tackling power inequities, discrimination and inequality at both an individual and collective level, have formed the basis of a distinct approach to working with and empowering service users.

The emergence of these ideas can be traced to challenges in the 1970s to the way that social work and welfare had individualized social problems affecting a range of social groups and that were ultimately to do with wider issues of political and structural inequalities in society.⁵⁴ Whilst early critiques concentrated on class and challenges to the pathologizing of the poor as

responsible for their own poverty, by the 1980s and 1990s, the focus had shifted to how a number of groups were oppressed in society on the grounds of their race, gender, disability and sexual orientation. This saw the emergence first of Black, anti-racist critiques,^{55–60} followed later by anti-discriminatory practice critiques covering disability,^{61,62} sexuality^{63,64} and age discrimination.⁶⁵

These ideas gradually became part of a broader framework called anti-oppressive practice (AOP) from the 1990s that has become widely used in social work and social care. This framework is based upon the premise 'that society is unequal and that the problems faced by service users have a personal, cultural and structural dimension'.⁶⁶ Challenging oppressive practice is seen as the driving force of anti-oppressive practice⁶⁷ alongside the empowerment of individuals and communities. These theories are considered to provide an important way of understanding some of the underlying factors underpinning involvement processes and the differentiated experiences of various groups, which have largely been ignored in patient safety.

From an AOP standpoint, for real change to occur, this will entail reappraising traditional and paternalistic power imbalances between users and professionals to take into account what users say they want, rather than imposing oppressive and non-negotiated solutions upon them. A mandate from users is seen to impose a dual responsibility on professionals to provide services that are non-oppressive (on grounds of age, disability or mental health, race, sex, sexuality or class status) and to be anti-oppressive in how they engage with users and their networks in challenging oppressive practice and experienced oppression.⁵⁸ This approach to empowerment is based not only upon tackling individually focused goals, but also oppressive and discriminatory social structures that exclude individuals and communities.⁵⁸

Building upon this thinking about critical approaches to user involvement in other parts of the public sector, this paper proposes a framework that could contribute to a more

critical and empowering approach to PPI in patient safety.

In the context of health and social care, it is difficult to evaluate how successful empowerment strategies to involve users have been, given the lack of evidence of impact and effectiveness.⁶⁸ Peck, Gulliver *et al.*⁶⁹ however, highlight trends in the 1990s coinciding with the empowerment of mental health service users in society. These have challenged professional narratives on the nature of mental distress, particularly in professions such as social work.⁶⁹ Beresford has also argued that the professions of social work and social care are certainly more advanced in the area of user involvement than other related academic disciplines and areas of professional activity. Even so, these professions are still viewed as having a long way to go in addressing oppressive and discriminatory practice.⁷⁰

Conclusions

This paper has argued that whilst there has been a considerable debate about increasing PPI in health care for many years, evidence suggests that progress has been variable in health care and considerably slower in patient safety. In the light of numerous policy imperatives and initiatives to address this matter, this paper suggests that what is lacking is a more critical, theory-driven approach to analysing processes underlying involvement. These are seen as frequently relating to issues of power inequities and control that have been well documented in looking at user involvement and participation in other parts of the public sector. This discourse has been largely lacking in discussions of PPI in the patient safety context. In order to broaden the debate about involvement, allow for a more nuanced approach to understanding the issues and address arguments about the need to evaluate its impact,^{68,71,72} it will be necessary to make more explicit the various factors that support and inhibit involvement processes and drive different types of involvement practice. This approach will be critical in the future in supporting the development of more systematic strategies for involvement in patient safety.

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