

Patient and public involvement in quality improvement



“How important and how simple it can be to genuinely listen to the views of patients and staff and engage them in how to improve services.”

Professor Sir Bruce Keogh, medical director,
NHS England

“I enjoy speaking to patients to understand their experiences and identify ways in which services could be improved.”

HQIP Service User Network (SUN) member



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1 Introduction

Patients and the public offer a unique voice to service development, identifying required improvements and inefficiencies first-hand as experts by experience.

This guide includes theory, rationale, and examples of best practice in the involvement of patients, service users, carers, and members of the public in quality improvement. Patient and public involvement (PPI) provides the timely opportunity for these groups to provide input as advocates for other patients, contributing to annual quality improvement (QI) programmes, and working in partnership with healthcare organisations, commissioners, and regulators, on individual QI projects.

PPI aims for the ongoing, transparent, and strategic-level partnership between healthcare organisations, patients, and the public, throughout quality improvement project life cycles, and, ultimately, patient-led activity.

1.1 Scope and purpose of the guide

This guide seeks to encourage and facilitate PPI in quality improvement projects, covering:

- ✓ Benefits of PPI in quality improvement projects
- ✓ Legal requirements for PPI in quality improvement projects
- ✓ Examples of PPI in quality improvement projects

A number of quality improvement projects are included as case studies at [Section 5](#) of this guide. These illustrate PPI through the application of various quality improvement methods. This guide is complemented by a range of additional HQIP materials available on the [HQIP website](#)¹ which we encourage users to consult in conjunction with this document.

Such materials include:

- [Guide to developing a patient and public involvement panel for quality improvement](#)²: step-by-step guidance for healthcare organisations planning a QI service user group. NB: A sample poster inviting participation is provided at [Appendix 2 of this guide](#)
- [Guide to quality improvement methods](#)³: an overview of a range of quality improvement techniques with which patients and the public might become involved
- [An introduction to quality improvement for patients and the public](#)⁴: certificated e-learning package to support patients and the public in understanding QI principles, covering a range of examples of how to become involved, and an overview of quality reporting

1.2 Who is this guide for?

This guide is aimed at those involved in QI in healthcare organisations, nationally, regionally or locally, whether patients, the public, managers, clinicians, or specialist quality improvement staff. Although written for use in healthcare, much of this guide can be adapted for use in social care settings.

1. HQIP's website: <http://www.hqip.org.uk/>

2. HQIP's Guide to developing a patient panel for quality improvement: <http://www.hqip.org.uk/resources/developing-patient-panels>

3. HQIP's Guide to quality improvement methods: <http://www.hqip.org.uk/resources/guide-to-quality-improvement-methods/>

4. HQIP's online learning package, an Introduction to quality improvement for patients and the public: <http://www.hqip.org.uk/resources/introduction-to-quality-improvement-for-patients-and-public/>

1.3 HQIP's PPI Strategy and seven principles of involvement

HQIP's *PPI Strategy*⁵ outlines several key aims, including:

- Patients, the public and healthcare professionals must work together to improve the quality of services
- Patients and the public need to be involved:
 - In the selection of projects to improve quality
 - In the governance of these projects, such as a clinical audit
 - As part of the dissemination of reports on findings and the resultant changes made
 - To ensure, as consumers, they are provided with reassurance, and choice of healthcare provider, where such a choice is realistic or possible
- Patients or their representatives should play a role in advising on the products or guidance HQIP develops as an organisation

HQIP adheres to the following seven principles of involvement, which it is hoped healthcare organisations will mirror, if not exceed, to capture the needs of patients for high quality services:

- 1. Representation:** Participating patients will be broadly representative of the relevant, affected population; consultations will be carried out through organisations such as *National Voices*⁶ in line with the *National Involvement Standards*⁷ (please see *Section 3* of this guide) to ensure broader representation on generic issues
- 2. Inclusivity:** HQIP will provide sufficient resources to overcome barriers such as issues of access or communication
- 3. Early and continuous:** Patients will be involved as early as possible in a process/activity and continue to be involved throughout, patients will be involved in all areas of HQIP's work
- 4. Transparency:** Those involved will be able to see and understand how decisions are made and information on audit data and consultant outcomes will be published in clear and understandable formats
- 5. Clarity of purpose:** The nature and scope of involvement will be defined prior to involvement; it will be clear how publications can be used to inform patients about the quality of services available
- 6. Cost effectiveness:** Involvement must add value and be cost effective
- 7. Feedback:** The outcomes of PPI activities will be fed back to participants; feedback on our products will be used to review and improve our publications

5. HQIP's Patient and Public Involvement Strategy: <http://www.hqip.org.uk/involving-patients/hqip-patient-and-public-involvement-strategy-2015-16/>

6. National Voices is an umbrella organisation bringing together a broad and diverse coalition of voluntary sector organisations, including HQIP, representing patients, service users and carers: <http://www.nationalvoices.org.uk/>

7. The National Involvement Standards are a framework produced by the National Survivor User Network around which to base standards for good practice, and to measure, monitor and evaluate involvement: <http://www.nsun.org.uk/assets/downloadableFiles/4pi-ni-standards-for-web.pdf>

2 Why involve patients and the public in quality improvement?

2.1 Examples of involvement in quality improvement

PPI is seen to enhance healthcare, and produce quality services that are oriented, planned and delivered to meet patient needs. Please see the case studies at [Section 5](#) for local Trust examples and below we have listed some international examples:



UK: The [Changing Our Lives](#)⁹ organisation supports people of all ages with learning disabilities to speak up for their rights and take control of their lives. Their work takes a community development approach, whereby local people and communities are best placed to find their own solutions to local problems. They have a team of quality auditors, all of whom have learning disabilities and experience of using care services, who receive regular training around confidentiality, safeguarding, observation skills, and audit. They lead person-centred [Quality of Life Audits](#)¹⁰ in a range of services, including residential homes, supported living centres, domiciliary care, and day services.



US: The Mayo Clinic medical centres set out to bridge clinical practice and human-centred design-thinking with their [centre for innovation](#)¹¹, using the SPARC (See, Plan, Act, Refine, Communicate) programme. Their innovation team work to understand people's needs and collaborate to design creative solutions to address those needs. Designers use exploratory methods such as observing patients, interviewing families, and traditional user research to uncover human needs in the healthcare environment. They also employ design tools such as visualisation, modelling, prototyping, and user-testing for quality improvement.



Australia: The [Australian Institute for Patient and Family Centred Care](#)¹² brings patients, families

and healthcare professionals together to transform people's experience of healthcare, and supports a patient-centred philosophy of care. Patients and their families are treated as partners with a significant role in the healthcare team. This includes involvement in hospital decision-making, as well as a central role in their own healthcare management so that they have a real voice in planning and implementing their own care. Information is rigorously shared so that families can make informed choices, and patient, family, and professional partnership collaborations are implemented at every level of their work.



US: The Virginia Mason Medical Centres and virtual visits aim to provide the perfect patient experience through the work of the [Virginia Mason Institute](#)¹³. Here, the needs of the patient come first – above everything and everyone. The institute teaches healthcare organisations how to implement and sustain a patient-centred approach to increase quality, safety and efficiency using lean methods of continuous improvement. Lean methods focus on reducing waste and inefficiencies and improving safety and consistency, with service user needs central to strategy. At Virginia Mason, putting patients first is at the heart of everything they do, as their most transformative element in quality improvement.

The involvement of patients and the public in service development provides a different perspective to that of clinicians and managers, and ensures that what is being measured, analysed and improved matters to patients, their relatives and carers.

9. Changing Our Lives: <http://www.changingourlives.org/>

10. Quality of Life Audit Standards: <http://www.changingourlives.org/wp-content/uploads/2015/08/QOLStandardsandToolkit.pdf>

11. The Mayo Clinic Center for Innovation: <http://www.mayo.edu/center-for-innovation/what-we-do/the-center-for-innovation>

12. The Australian Institute for Patient and Family Centred Care: <http://www.aipfcc.org.au/>

13. The Virginia Mason Institute: <https://www.virginiamasoninstitute.org/>

2.2 Priorities

In their publication, ‘Missed opportunities for impact in patient and carer involvement’, Snow et al write¹⁴:

“A major cause of medical research ‘waste’ is lack of attention to the real-world needs of those who would benefit from research. This can be seen in the apparent mismatch between research agendas and the expressed needs of patients and carers.”

Snow et al

Snow et al explain that there have been calls for the gap between healthcare research and real-world needs to be closed by inviting patients and carers to help shape priorities, and that if healthcare services are to deliver patient-centred care, then the evidence base provided needs to be more reflective of service user needs and concerns. They state:

“Involvement of service users in identifying and prioritising medical research questions and topics should help to ensure that research being conducted is relevant to them. Such involvement can broaden the scope of a proposed research agenda and help to ensure that it is grounded in the day-to-day reality of service users’ experiences.”

Snow et al

2.3 Impact

Reported impacts of PPI upon research projects, identified through literature review¹⁵, are:

- Impact on the research agenda – the topic, research question and funding decisions
- Impact on research design and delivery – influencing the research design, tools and choice of method, recruitment, data collection and analysis, writing-up and dissemination
- Impact on research ethics – the consent process and developing ethically acceptable research
- Impact on the people involved
- Impact on the researchers
- Impact on participants
- Impact on the wider community
- Impact on community organisations
- Impact on implementation and change

The Department of Health has published a range of guidance and legislation to promote PPI within health and social care, and strives to ensure that it is incorporated into NHS decision-making and service improvement processes. Key requirements are highlighted at [Appendix 1](#).

As an illustration, the NHS National Institute for Health Research Devices for Dignity Healthcare Technology Co-operative outline a thorough, robust and effective approach to PPI for quality improvement, from notification of an unmet need through to project conclusion, in this [short video](#)¹⁶.

14. Snow, R., et al, 2015. *Missed opportunities for impact in patient and carer involvement: a mixed methods case study of research priority setting*. Research Involvement and Engagement

15. Staley, K., 2015. *‘Is it worth doing?’ Measuring the impact of patient and public involvement in research*. Research Involvement and Engagement

16. NHS National Institute for Health Research Devices for Dignity Healthcare Technology Co-operative video, Patients Leading Innovation – Devices for Dignity: www.youtube.com/watch?v=BztMLGWu_t4

2.4 Models of involvement

Academic literature provides a theoretical and conceptual model of PPI. Historically, Sherry Arnstein's¹⁷ ladder of participation (Figure 2) has been used to describe the ways in which a patient or service user may wish to become involved, or the level of involvement an organisation has reached.

The ladder places **informing** patients and the public of the services available, and the results of a quality improvement project as low level involvement.

Consultation is often mistaken as high level involvement, and commonly interpreted as sending out a survey, rather than consultative interviews, focus groups and workshops. It is placed in the middle of the ladder and considered a lower level of involvement than actually engaging and partnering with patients and the public.

Partnership is a high level involvement, which means working together to develop a quality improvement project from the outset, with potential for some projects to be **patient-led**, for truly person-centred improvements to the quality of care.

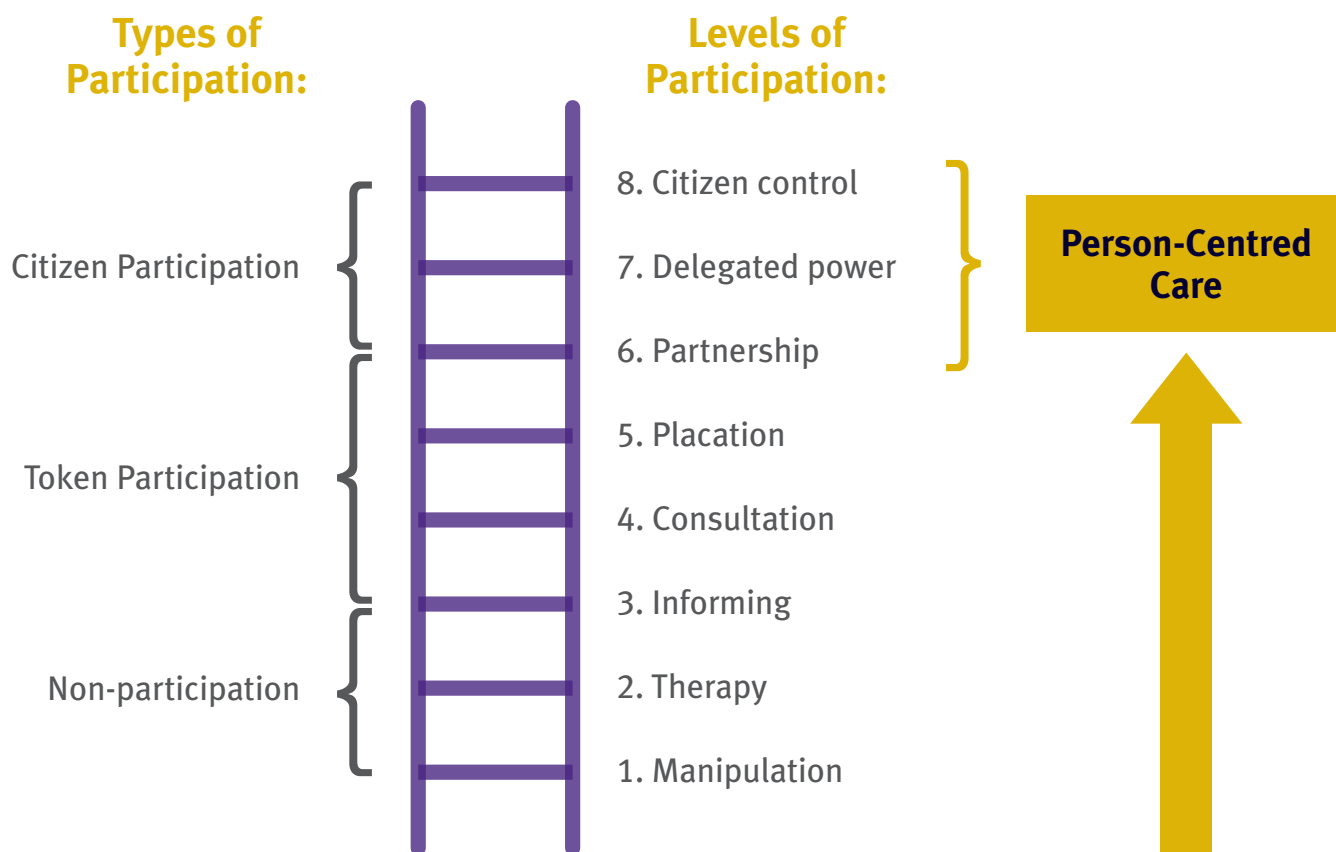


Figure 2 Ladder of Participation, adapted from Arnstein's Ladder¹⁷

17. Arnstein, Sherry R., 1969, *A Ladder of Citizen Participation*. Journal of the American Planning Association

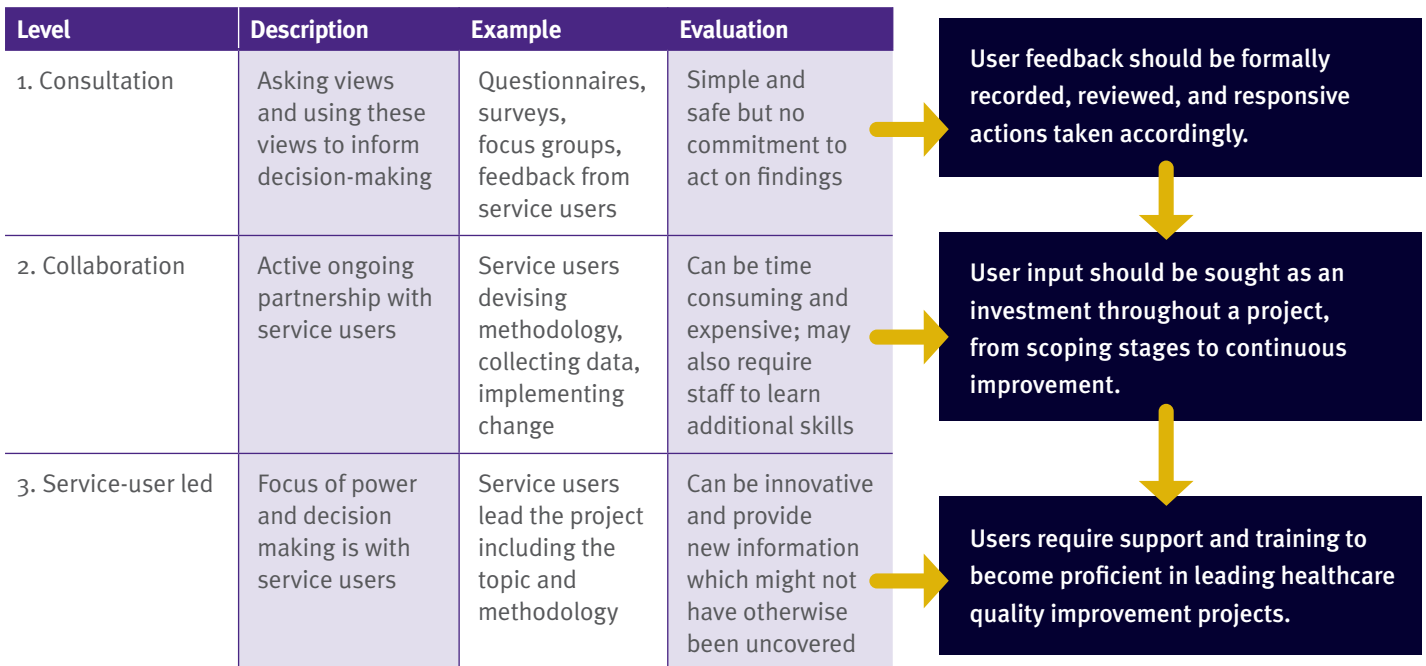


Figure 3 Three Levels of Involvement, adapted from Hanley et al¹⁸

Similarly, Hanley et al place three levels of involvement along a continuum culminating in activity that is **service-user led**¹⁸ (Figure 3).

Examples of collaboration, partnership and service user led quality improvement can be seen within the case studies in [Section 5](#) of this guide, ‘Case study examples of PPI in quality improvement’.

2.5 Benefits of patient and public involvement in quality improvement

2.5.1 Providing views of experts by experience for unique insight

Those who have lived with a particular illness can become experts in that condition, as can their carers. The patient has a unique and subjective viewpoint based on actual first-hand experience about where quality could, and should, be improved.

2.5.2 Offering different perspectives to staff

Patients’ direct experience of care gives them a different viewpoint on ways to improve the quality of a service, in terms of care needs, quality of life and wellbeing. Patients and clinicians will make different choices about the various elements of care that are reflected in standards and measured by quality improvement projects.

“The resulting actions are already taking us in directions **I could never have imagined**, such as user co-design of maternity notes, improving antenatal information for fathers, and starting a midwifery team Twitter account.”

Florence Wilcock, consultant obstetrician, Kingston Hospital, after a quality improvement exercise with patients and the public: Whose Shoes?

18. Hanley, B., et al., 2004, *Involving the public in NHS, public health, and social care research: Briefing Notes for Researchers*, Eastleigh: Involve

2.5.3 Creating a service more aligned to patient needs

By participating in quality improvement programmes, patients and the public influence services to meet their needs. They enhance quality improvement projects by assisting in developing these, scrutinising the action plans that address concerns they've raised, and providing a clearer picture to staff of the changes needed within a service, from the patient's perspective.

“Moving on from being the passive recipients of services, **actively involving** people in a true and meaningful way, is a reflection of a positive culture.”

HQIP Service User Network (SUN) member

2.5.4 Helping inform choice

The results of a quality improvement project provide patients and the public with more knowledge about the quality of care in a particular healthcare setting. They enable more informed choice, where this is possible, about where to obtain treatment. Quality improvement project results should therefore be shared so that they are accessible to the public, i.e., easy to find and written so that they are clear, with transparent conclusions and data. *HQIP's guide to how to present a patient-friendly clinical audit report*¹⁹ illustrates the requirements of clear *quality improvement reports*²⁰, and highlights that any report being prepared for patients and the public requires their involvement in its development.

“**Patients are the experts** in recognising good and bad service delivery. They are on the receiving end.”

HQIP Service User Network (SUN) member

Public reporting boosts public confidence in the NHS and builds trust and satisfaction. PPI in quality improvement enables a deeper understanding amongst patients and the public of the challenges of providing healthcare²¹. Provider organisations should not suppress quality improvement project results that are negative or critical of care, as these present opportunities for discussion and progress towards improvement. The *NHS Standard Contract*²² states that healthcare providers must actively engage, liaise and communicate with service users, their carers and guardians, in an open and clear manner, seeking their feedback whenever practicable, and must involve them when considering and implementing developments to, and redesign of, services.

“Quality improvement is achieved through **partnership** between clinicians and patients.”

HQIP Service User Network (SUN) member

Many clinicians, and some managers, are concerned about quality improvement project data being used to inform patient choice. They may feel that the primary purpose of a quality improvement project is internal review of compliance with clinical standards, with concerns that quality improvement project data can be difficult to understand and require specialist interpretation and context for meaning to be clear. For example, straight like-for-like comparisons can be problematic as issues of case-mix may mask variation in clinical competence, and lead to uninformed expressions of choice, rather than informed choice.

Inevitably there must be balance. Many patients neither want nor need to exercise choice, but want to be able to receive quality healthcare services everywhere. In this context, choice is a diversion from the pursuit of universal high standards. Nonetheless, patients and the public have a right to know whether a unit or *individual practitioner*²³ is competent, rather than assuming that they are.

19. HQIP's guide, How to develop a patient friendly clinical audit report:

<http://www.hqip.org.uk/public/cms/253/625/19/47/How%20to%20develop%20a%20patient-friendly%20clinical%20audit%20report.pdf?realName=4My1Ej.pdf>

20. National Joint Registry (NJR) Patient and Public Guide to the NJR's 11th Annual Report 2014: http://view.digitalissue.co.uk/go/njrpublicandpatientguide_hipediton2014/

21. Department of Health, 2010, Equity and Excellence: Liberating the NHS

22. The NHS Standard Contract: <https://www.england.nhs.uk/wp-content/uploads/2016/04/2-nhs-ill-length-1617-scs-apr16.pdf>

23. NHS Choices: Consultant outcome data: <https://www.nhs.uk/service-search/performance/Consultants>

Those who participate in quality improvement projects should share their results clearly, openly, and transparently, with appropriate caveats enabling accurate comparisons and conclusions to be drawn. Sharing data can highlight pockets of best practice for collaboration and universal improvement.

2.5.5 Helping improve health

Strong social support networks such as family, friends, and peers are known to benefit health, and an associated increase in confidence and self-esteem are directly related to health and wellbeing. Being involved in improving the quality of healthcare can bring health benefits to patients and their families through the satisfaction of having influenced care, being listened to, gaining further insight into their issues, and the social interaction and engagement that involvement offers.

“As a patient, being involved in quality improvement was a key stepping stone in my recovery.”

HQIP Service User Network (SUN) member

2.5.6 Engaging people with services available

Patients and the public are not always aware of the services available to them, and PPI fosters community engagement to improve population health.

Finding people to get involved in quality improvement can be difficult. HQIP’s guide to developing a patient and public involvement panel for quality improvement offers practical guidance to assist. National consumer champions for people who use health and social care services, such as [Healthwatch England](#)²⁴, [Community Health Councils](#)²⁵ in Wales, [The Scottish](#)

[Health Council](#)²⁶, and [The Patient Client Council](#)²⁷ in Northern Ireland, ensure that the voices of service users are heard and responded to. They may also provide connections for Trusts to access interested and enthusiastic patients and members of the public who want to be involved in quality improvement projects.

There are further opportunities to reach out to people who want to comment and give their views, but who do not necessarily want to be extensively involved, for example, through the use of electronic and social media. The various websites that exist to channel patients’ views about the care they receive, such as [Patient Opinion](#)²⁸, offer opportunities to widen the pool of potential participants.

2.5.7 Responding to local needs

Communication with other local patient and public forums and organisations helps to ensure the development of quality improvement projects that are responsive to local needs. Patients and the public feel a greater ownership of healthcare services if they are consulted and listened to, which contributes to a more cohesive society and active citizenship. Local branches of organisations such as [Healthwatch England](#)²⁴ and [Data for better services](#)²⁹ offer insight into people’s experiences with local health and social care services; they provide eyes and ears on the ground, sharing what matters to local communities.

2.5.8 Developing appropriate indicators to help improve care

Patients and the public as service users have an essential role in determining what constitutes high quality care and contributing ideas for improvement. Their involvement in quality improvement enables insight into their preferences for suitable indicators as measures of the quality of care provided, and identifying what is needed to maintain and improve the quality of care in future³⁰.

24. Healthwatch England are the consumer champion for health and social care: <http://www.healthwatch.co.uk/>

25. Community Health Councils ensure health services listen to patients views in Wales: <http://www.wales.nhs.uk/sites3/home.cfm?ORGID=236>

26. The Scottish Health Council promote patient focus and public involvement in the NHS in Scotland: <http://www.scottishhealthcouncil.org/>

27. The Patient and Client Council provide an independent voice for people in Northern Ireland: <http://www.patientclientcouncil.hscni.net/>

28. Patient Opinion are an independent organisation set up to receive feedback about health and social care services, and share it with the right people to make a difference: <https://www.patientopinion.org.uk/>

29. My NHS - Data for better services: <https://www.nhs.uk/Service-Search/performance/search>

30. NHS England’s mission to secure high quality care for all – now and for future generations: <https://www.england.nhs.uk/about/our-vision-and-purpose/imp-our-mission/high-quality-care/>

3 Carrying out a PPI impact assessment

PPI in quality improvement should be meaningful and make a difference. It should result in service improvement, and enhance the health and wellbeing of patients and service users.

The National Survivor User Network (NSUN) hosts the National Involvement Partnership (NIP) project, funded by the Department of Health. The project has produced national standards for the involvement of service users in mental health and social care services, to build the service user and carer voice and experience into the planning, delivery and evaluation of health and care services. It promotes user and carer leadership, realising the vision ‘nothing about us without us’. In line with their *National Involvement Standards*³¹, the following five questions should be asked to assess the impact of each involvement project, with service users providing input into responses:

1. What were the intended outcomes of the involvement activity?
2. What actual difference(s) have service users and carers made to the project, activity or organisation? (This can be monitored by continuous recording throughout a project as well as assessment at the end)
3. How did everyone feel about the process of involvement? (e.g. using ‘end of involvement’ questionnaires)
4. Did the involvement of service users and carers make a difference to the end result of the activity/project?
5. Did the involvement of service users and carers make a difference beyond the activity itself – to the delivery of services or the understanding of mental health, to the recovery or wellbeing of individuals?

³¹. The National Involvement Standards are a framework produced by the National Survivor User Network around which to base standards for good practice, and to measure, monitor and evaluate involvement: <http://www.nsun.org.uk/assets/downloadableFiles/4pi-ni-standards-for-web.pdf>

4 Quality improvement

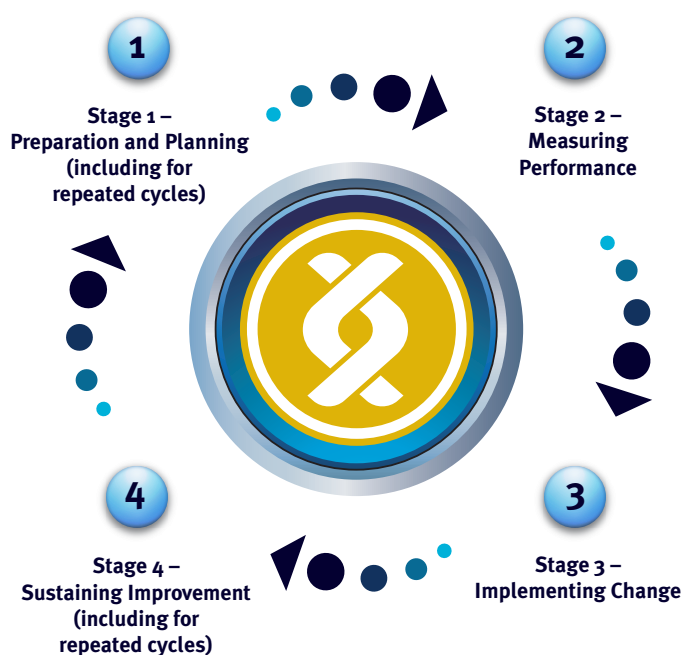
This section of the guide provides a brief overview of quality improvement. Quality improvement staff will already have a greater understanding of the subject, however this section is intended to be useful to other staff, patients, service users, carers, and members of the public.

4.1 What is quality improvement?

Quality improvement in healthcare is a process that seeks to enhance patient safety, outcomes, and experience, through measuring and improving the effectiveness of clinical services provided. Quality improvement projects should therefore measure what is important to patients.

4.2 The quality improvement cycle

HQIP's quality improvement cycle includes four main stages:



Stage 1 – Preparation and Planning (including for repeated cycles):

- Patient and public involvement
- Organisational arrangements
- Stakeholder engagement

Stage 2 – Measuring Performance:

- Quality improvement methodology
- Data collection process
- Data analysis and reporting

Stage 3 – Implementing Change:

- Action plan development (including actions to take forward recommendations made)
- Take actions

Stage 4 – Sustaining Improvement (including planned for repeated cycles where necessary):

- Repeat quality improvement project/study
- Continuously improve until changes are effective

Involvement of patients and the public throughout the entire cycle is vital to ensure optimum quality improvement. [HQIP's guide to quality improvement methods](#)³ offers an overview of a range of quality improvement techniques with which patients and the public might become involved.

5 Case study examples of PPI in quality improvement

In this section of the guide we present selected case studies demonstrating a variety of ways in which patients and the public might be involved in quality improvement in healthcare.

The following case study incorporates the action effect method, process mapping, and the Plan, Do, Study, Act (PDSA) technique, used to co-design a physical assessment and action planning tool to improve the physical healthcare of patients:

Case study:

Service user co-design of an inpatient physical health plan

This submission demonstrates:

- Service user co-design to create a patient-centred tool
- Benefits of collaboration
- Use of a range of quality improvement methods

September 2015

Collaboration for Leadership in Applied Health Research and Care - Northwest London, with Central Northwest London NHS Foundation Trust

<http://clahrc-northwestlondon.nihr.ac.uk/>

Summary

Central Northwest London NHS Foundation Trust brought together a team of service users, quality improvement experts, and healthcare professionals, to systematically improve the physical healthcare of patients admitted to a mental health ward.

Service users have been pivotal in developing a patient physical health plan, which offers patients individualised advice about their physical health. It has been developed using process mapping and tested through plan, do, study, act cycles, before roll out on a wider scale at the Trust.

Background

Central Northwest London NHS Foundation Trust (CNWL NHSFT) worked with the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Northwest London on a Health Foundation-funded project that used quality improvement methods to develop and implement a tool to ensure all patients admitted to hospital have their physical healthcare needs met.

People with serious mental illness have a significantly reduced life expectancy and a higher prevalence of physical health disorders than the general population. 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 or diabetes and provide advice and support on services that can be accessed on discharge. Unfortunately this is rarely done for patients with serious mental illness when they are in hospital, despite numerous national guidelines recommending such an approach.

Aims

- Improve the physical healthcare of patients admitted to a mental health ward
- Roll out the improvements on a wider scale across the Trust

Objectives

- Develop a shared vision for quality improvement with the project team, including service users, quality improvement experts and healthcare professionals
- Identify gaps in physical health assessment in those with serious mental illness
- Co-design a patient-centred tool to support improvement in physical health
- Test and refine solutions on a small scale, within a single hospital ward, before roll out across the Trust

Approach

Service user involvement was facilitated through the use of the [4PI Standards⁷](#), a simple, yet robust framework around which good practice can be based. It aims to measure, monitor and evaluate involvement, comprising standards of: Principles, Purpose, Presence, Process and Impact.

The action effect method was used to guide the project. This is a systematic and structured process to identify and articulate a quality improvement initiative's programme theory to the team, to underpin activities and interventions. Ensuring people with a lived experience of serious mental illness were involved as full members of the project team and the advisory board was essential to ensure their perspectives were considered.

Process mapping was implemented to review the care pathways associated with admission, analyse current practice and identify where improvements could be made and interventions introduced. An initial clinical audit of the recording of physical healthcare parameters identified the need for a more robust and streamlined assessment and recording system, developed by the healthcare professionals themselves using plan, do, study, act cycles.

The new physical healthcare assessment included the calculation of a JBS₃ Score, which estimates an individual's lifetime risk of developing cardio-vascular disease. Using the principles of 'measuring for improvement', weekly measures were established to assess the uptake of the assessment tool. Data has been captured on the Web Improvement Support for Healthcare (WISH) system, developed by CLAHRC Northwest London, which provides real-time analysis of data using statistical process control.

In addition to the new physical healthcare assessment, service users and healthcare professionals worked together to co-design a personalised physical healthcare plan for patients.

Challenges

- Keeping all team members engaged through project peaks and troughs, and the bureaucratic pace of change
- Supporting service users and healthcare professionals to work together with a shared vision

Outcomes

Aside from a physical assessment tool and action plan, the project has led to the co-production of a patient held physical health booklet as a tool for shared decision-making around physical health. The booklet uses a traffic light system to explain risks and enable patients to take some responsibility for improving their physical wellbeing.

The project team has also been provided with the 'Long Term Success' tool, designed by CLAHRC Northwest London, to help them reflect on progress and identify challenges to sustaining improvements in the clinical setting.

Conclusion

The project is currently being implemented on just one ward of the mental health unit and will be rolled out further across the unit. The physical healthcare plan has the potential for use more widely across the organisation, including in community clinics. The success of the project in engaging service users is due to be highlighted in the journal, "The Lancet Psychiatry", to help share the practice nationally.

Feedback

“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.”

Sandra, project team member with lived experience of mental health problems

“I’ve been involved in many projects over the years, but this is the first time I’ve really felt part of a team.”

Jenny, project team member (service user)

Contact details

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NIHR CLAHRC Northwest London
07889 179 020
liz.evans@imperial.ac.uk



Case study:

Co-designed escalation assessment and training

Clear communication is important in high quality healthcare, and aids such as the Situation, Background, Assessment, Recommendation (SBAR) tool, designed with service users in the following case study to improve the escalation process, can prove essential in managing human factors:

This submission demonstrates:

- Improved communication
- Meaningful assessment and action
- Effectiveness of co-design

September 2015

West of England Academic Health Science Network

www.weahsn.net

Summary

The West of England Academic Health Science Network commissioned a project led by Sirona Care and Health and North Bristol NHS Trust, to work with service users to co-design an escalation assessment and training package involving communication skills and human factors. The project was funded by Health Education South West and was aimed at support staff working in the community and in residential homes.

Teamwork, communication and leadership were improved through the development of a Situation, Background, Assessment, Recommendation (SBAR) tool, with training involving real-life scenarios.

Background

In the interests of a more cohesive and joined up approach to escalation assessment for improved quality of care, the West of England Academic Health Science Network (WEAHSN) commissioned a project, led by Sirona Care and Health and North Bristol NHS Trust, to work with service users and support staff to co-design a new system and process, funded by Health Education South West.

Co-design was felt to be extremely important in the interests of exploring the perspectives of all involved, to produce an

efficient and effective system of escalation that met service users' needs when at their most vulnerable. WEAHSN tries to involve patients and members of the public as co-producers in all its work streams.

Service users were keen to take part and share their experiences, which were fed into the new system design and associated training package.

Aims

- Stronger escalation assessment communication
- Improved team-working across staff groups
- Supported leadership

Objectives

- To strengthen communication at escalation and handover through use of the SBAR tool
- Consistent documentation and approach to escalation across the team, using the SBAR tool combined with training across staff groups
- Leadership supported through an agreed approach to escalation

Approach

- Scenarios using the SBAR tool were co-designed through service user participation workshops
- Service users were invited to share from their first-hand-

experience the circumstances in which the SBAR tool might be used

- Scenarios were drawn up from real life service user stories to be used in staff training
- Support staff and care assistants were trained in the use of the SBAR tool linked to the early warning score, including its application to the scenarios developed with service users; this aimed for consistent documentation and approach to escalation across the team
- Leadership was supported through an agreed, shared and documented approach to escalation assessment using the SBAR tool

Challenges

As the use of an SBAR tool for escalation in community and residential care is a new concept, there was no baseline from which to measure improvements associated with its introduction.

However, now that the tool is in use and training has been carried out for staff, measurements will be collected using current practice, with improvements evaluated over time and linked as far as possible to specific changes in practice.

Outcomes

The West of England Academic Health Science Network recently had a visit from Sir Keith Pearson of Health Education England to see how the initiative was improving the quality and safety of care for residents in the community.

While improvements resulting from the initiative are as yet unmeasured, for individuals and the system as a whole improvements have been clear.

Using a common language across health and social care enables the best outcomes, especially for those service users with complex health needs. When everyone uses the same language, communication greatly improves. For example, with the introduction of the SBAR tool and associated training, one community resident who was regularly admitted to hospital has not been admitted since.

With the SBAR tool linked to the early warning score, staff are trained to recognise and respond to deterioration in someone's health or circumstances, in line with recently published

National Institute of Health and Care Excellence (NICE) guidance (Home care: delivering personal care and practical support to older people living in their own homes).

Conclusion

The exercise demonstrated the importance of involving service users in the design of systems and processes that involve them.

Service users enjoyed taking part, learning, and sharing their experiences, which were important to the entire project and made for better outcomes overall. Staff very much enjoyed working with them for their refreshing perspective and valuable input.

With repeated test cycles to measure improvements associated with the introduction of the SBAR tool and training against an initial baseline, as well as co-design, the quality of the tool and training will improve further over time.

The need to train leaders in taking a wide range of actions as a result of an SBAR assessment has already been identified as a next step, and is being arranged.

All who have taken part in the exercise look forward to measurable improvements through forthcoming quality improvement study cycles.

Feedback

“SBAR has made situations clearer and much easier to understand.”

“SBAR has helped me to think about the way in which I pass on information, and how best to get straight to the point.”

Comments from training participants

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Case study:

Co-produced support for carers of those with dementia

Inclusivity is key in successful PPI activity, and it is important to capture the views of different age groups, including children, teenagers, those who are out at work, the elderly, and vulnerable and inaccessible groups who are often most in need of improvements to the quality of services.

The following case study illustrates a quality improvement initiative involving those who may reach crisis point caring for people living with dementia, through collaboration across the local commissioning, health and care landscape:

This submission demonstrates:

- Quality improvement across the healthcare landscape
- Training carers to interview other carers
- Difficulties of accessing hard to reach groups

September 2015

NHS Luton Clinical Commissioning Group

www.lutonccg.nhs.uk/home

Summary

After GPs and nurses in Luton raised concerns with NHS Luton CCG about the number of carers for people living with dementia reaching crisis point, collaborative action was agreed to understand the issues carers faced, and to address those issues to improve the quality of their experience.

Delivering public services through an equal and reciprocal relationship between professionals, people using those services, their families and their neighbours was felt to be key to the success of the project, and the decision was taken to train and involve carers in the examination of issues, to help identify potential solutions from their perspective.

Background

A collaborative project was developed by NHS Luton Clinical CCG as lead, in partnership with people living with dementia, carers of people with dementia, Age Concern Luton, Alzheimer's Society, Cambridge Community Services, GPs,

Keech Hospice Care, Luton Borough Council, Luton & Dunstable NHS Foundation Trust, South Essex Partnership Trust and East London Foundation Trust. The project used a co-production approach to identify what can be improved in Luton for carers of people living with dementia, after GPs and nurses had raised concern that many such carers were reaching crisis point.

Aims

- Identify what could be improved or introduced in Luton to reduce carer stress and breakdown
- Establish and review co-production as a methodology for project development, through the involvement of people living with dementia, their carers, and the various professionals with whom they interact

Objectives

- Develop, use and evaluate a co-production process between statutory sector professionals, carers of people living with dementia and charity/voluntary organisation professionals
- Identify the key causes of stress and potential breakdown for carers of people living with dementia
- Agree solutions to the causes identified, with where possible, short, medium and long-term recommendations

- Evaluate the co-production process and project findings
- Share findings and evaluation locally and potentially nationally (depending on evaluation)

Approach

A project co-ordinator and project implementation Board were established, along with terms of reference and monthly meetings, with a finance sub group, who agreed finance protocols including a travel claim form and invoicing processes.

A one-off consultative sub-group devised key research questions and a timetable for study, agreed carers would themselves interview other carers for optimal learning, and set out their training needs and the process for engagement.

Three training workshops were planned for carers to become project interviewers and interview other carers.

A press release was issued via Twitter and Facebook feeds, and a consent form was shared with carers initially interested in taking part. This was to be completed ahead of a telephone call back to answer preliminary research interview questions:

- What are the things that you find most difficult? What do you worry about?
- What are the one or two things that would support you in your caring role? What is the one thing that you think – ‘If only I had that, it would make so much difference?’

Telephone research interviews have commenced, feedback is being collated and a workshop involving carers has been held to review the co-production process so far.

Challenges

- Recruiting carers to participate, because some cannot find the time to take part
- Recruiting sufficient carers to be interviewed to give a large enough sample size to be valid
- Ensuring carers are physically and emotionally supported throughout the process

Outcomes

Although the project is still underway, stronger relationships and partnerships have already been established across the dementia care environment within Luton, and where identified as supportive, early interventions have already helped those in need.

Service redesign will be delivered through a co-productive process with carers of people living with dementia engaged throughout development.

In the longer-term, a reduction in the causes of carer stress and breakdown should result, with effective support enabling carers and people living with dementia to stay in their own homes longer.

Conclusion

The findings of the project will be presented to NHS England, the East of England Strategic Clinical Network Programme Board, and NHS Luton CCG members.

The findings will also be shared with other CCGs and statutory partners, and were presented to stakeholders at the Luton Dementia Conference in November 2015.

Feedback

“GPs and nurses in Luton raised concern at the number of people caring for those with dementia reaching crisis point, and we decided to collaborate to take action.”

“Carers taking part in the initiative felt glad we were listening and have welcomed the support.”

Caroline Faulkner

Business manager, Keech Hospice Care

Contact details

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Case study:

Whose Shoes? #MatExp (Maternity Experience)

The most productive and effective quality improvement work is engaging, and takes place in a relaxed, non-judgemental environment, led by a facilitator without hierarchy, so that all involved feel free to comment, are listened to, and able to be creative in devising solutions. This is illustrated by the following case study, which demonstrates innovative methods of involvement to improve the quality of the maternity care experience:

This submission demonstrates:

- Co-participation in service quality improvement
- Integrated perspectives for effective change
- Devolved leadership for person-centred care

August 2015

Kingston Hospital NHS Foundation Trust

<http://www.kingstonhospital.nhs.uk/>

Summary

Through collaboration between the London Maternity Strategic Clinical Network, NHS England, a Kingston Hospital NHS Foundation Trust consultant obstetrician, hospital staff, commissioners, service users and the creator of “Whose Shoes?”, “#MatExp” (Maternity Experience) was born. This pilot project combined a thought provoking board game with open and transparent discussion in a supportive workshop environment, as the catalyst for in-depth analysis, pledges to improve the quality of services, and rapidly agreed change.

Background

The workshop was designed to look at experience of maternity services from all perspectives, and challenge assumptions, focusing on treating women and their families with dignity, compassion and respect. The workshop was the first of a series of five planned across London. Using lively facilitators and engaging tools such as a board game incorporating

key questions, and plenty of refreshments, the relaxed and inclusive workshop enabled participants to:

- Openly discuss key local issues with hospital staff at all levels
- Identify the things that needed to change and understand why change mattered
- Agree how changes should be made
- Pledge to make the changes agreed

Gathering mixed groups around a board game, babies welcome, got the creative sparks flying. Throughout the workshop it was acknowledged that each person was present in multiple capacities. Professionals are also mothers, fathers, sisters, friends and family with their own stories and birth experiences, and service users bring knowledge and expertise from other aspects of their lives such as their job, culture and education. All of this is invaluable, and alongside respect and equality, form essential ingredients to the success of the workshop. Discussions embraced the assumptions that “best can always be better” and “wrong is wrong, even if everyone is doing it, and right is right, even if no-one is doing it”.

Aims

- A maternity service that meets user needs
- Understanding the needs of all participants
- Integrated analysis for rapid improvement

Objectives

- To use real scenarios from users and staff to examine the maternity experience from all angles and perspectives
- To provide a comfortable environment enabling all involved to freely share their experiences without judgement
- To jointly discuss and agree changes required in depth from all perspectives

Approach

The half day workshop was advertised, and 40 people arrived: mothers with their babies, service users who had previously felt cause to complain, and a range of staff. All were given name badges to wear without hierarchy, and assembled in groups at five tables, each with a copy of the board game to play to stimulate discussion around known local issues. A welcome, introductions and guidance for attendees at the workshop were provided, along with courageous stories from users. All were invited to use Post-it notes to capture key ideas and solutions throughout the session, whilst a graphic facilitator, Anna Geyer of New Possibilities, recorded them on a visual chart.

Challenges

The open nature of discussions and personal stories of experiences shared by users (including the consultant obstetrician as a user) were powerful and sometimes difficult to hear, but provided essential input.

Outcomes

At the end of the workshop each attendee was asked to pledge what they as an individual would do differently to improve the maternity experience, which combined with the

visual chart became an action plan for the service. Pledges brought a personal sense of responsibility for the actions required, so that each outcome was not the sole responsibility of hierarchical leaders, but of everyone involved. Quality improvements will be made through the implementation of the action plan, with metrics to measure improvements where applicable. Resultant changes include:

- User co-design of maternity notes
- Care using the word “failure”, for example, as in “failure to dilate”
- Improving antenatal information for fathers
- Starting a midwifery team Twitter account
- A ward graffiti board for ongoing feedback
- Extending the workshops to other Kingston Hospital departments

Conclusion

Despite believing herself to be already very “person centred”, as a result of working on the project the consultant obstetrician has found a succession of small but important changes spilling into her own everyday practice – thinking increasingly carefully about her choice of language and behaviour. For example:

- No more “are you happy with that?”, but “how does that sound to you?”
- Explaining attendance on a ward round
- Having the woman’s partner in theatre for the general anaesthetic so they don’t both miss the birth
- Using intense listening techniques to understand women’s perspectives in clinic

The workshop energised people to act upon their ideas, leading to a wider Kingston Hospital #KHFTWhoseShoes improvement project, and a social media explosion of “Mum Leaders” – with one mother setting up her own survey online independently and sharing her findings.

Feedback

“The aim is to use the workshop as an ‘ignition tool’ to build connections and relationships across the broad maternity community. We want to enable true collaboration, co-design and ongoing conversations to improve the maternity user experience.”

“The workshop harnessed the power of walking in the shoes of others.”

Gill Phillips

Creator of Whose Shoes?

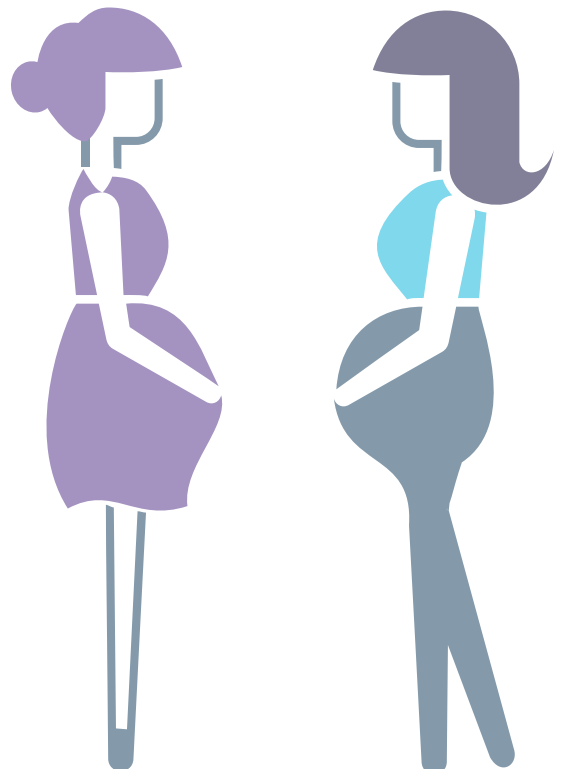
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For more information, please visit the London Maternity Strategic Clinical Network website:
<http://www.londonscn.nhs.uk/networks/maternity-childrens/maternity>

A ‘Maternity Experience Workshop’ guide outlining the key steps to deliver a workshop is available here: <http://www.londonscn.nhs.uk/wp-content/uploads/2014/11/mat-user-experience-toolkit-022015.pdf>



6 Summary

Involvement of patients and the public in quality improvement projects is a marker of effective improvement and a precursor to high quality care. In essence, the involvement of patients and the public, both nationally and locally in quality improvement projects should include:

- Involvement in the **strategic direction** of quality improvement projects
- **Partnership** in respect of standards (and outcomes, where appropriate) to be measured
- **Active participation** in data collection where possible, e.g. through interviews or surveys, and analysis and scrutiny of quality improvement project data
- Involvement in **communications** around quality improvement activity
- Involvement in quality improvement project **governance**

To be effective, PPI should run through the full cycle of every quality improvement project, as an integral part of the fabric of the whole project.

This guide offers support for PPI in quality improvement that can be adapted to suit local needs. We hope it provides organisations with the confidence required to include PPI within all quality improvement projects.

Please contact [Kim Rezel](#) with your examples of successful PPI in QI projects, and with your feedback on this guide.

7 Further reading

[*HQIP's guide to developing a patient and public involvement panel for quality improvement*](#)²

[*Confidentiality agreement template example*](#)³²

[*HQIP's guide to quality improvement method*](#)³

Further case studies and much more is available on [HQIP's website](#)¹.

³². Confidentiality agreement template examples: <http://www.hqip.org.uk/resources/developing-clinical-audit-patient-panels/>

Appendix 1 – Guidance and legislation for patient and public involvement

[Care Quality Commission, Guidance for providers on meeting the Health and Social Care Act 2008 \(Regulated Activities\) Regulations³³, 2014 \(Part 3\) \(as amended\) Care Quality Commission, March 2015, Regulation 17: Good governance:](#)

As part of their governance, providers must seek and act on feedback from people using the service, those acting on their behalf, staff and other stakeholders, so that they can continually evaluate the service and drive improvement.

UK Legislation, [Health and Social Care Act, 2012³⁴:](#)

Introduced significant amendments to the NHS Act 2006, especially with regard to how NHS commissioners will function. These amendments include two complementary duties for clinical commissioning groups with respect to patient and public participation:

- Individual participation duties: Clinical commissioning groups (CCGs) and NHS England must promote the involvement of patients and carers in decisions which relate to their care or treatment. This requires collaboration between patients, carers and professionals, recognising the expertise and contribution made by all. The duty requires CCGs to ensure that they commission services which promote involvement of patients across the full spectrum of prevention or diagnosis, care planning, treatment and care management.
- Public participation duties: The second duty places a requirement on CCGs and NHS England to ensure public involvement and consultation in commissioning processes and decisions. A description of these arrangements must be included in a CCG’s Constitution. It includes involvement of the public, patients and carers in:
 - planning of commissioning arrangements, which might include consideration of allocation of resources, needs assessment and service specification.
 - proposed changes to services which may impact on patients.

[NHS Standard Contract³⁵ 2016-17, Service Conditions, SC12 Communicating with and involving Service Users, Public and Staff:](#)

12.3 The Provider must actively engage, liaise and communicate with Service Users (and, where appropriate, their Carers and Legal Guardians), Staff, GPs and the public in an open and clear manner in accordance with the Law and Good Practice, seeking their feedback whenever practicable.

12.4 The Provider must involve Service Users (and, where appropriate, their Carers and Legal Guardians), Staff, Service Users’ GPs and the public when considering and implementing developments to and redesign of Services. As soon as reasonably practicable following any reasonable request by the Coordinating Commissioner, the Provider must provide evidence of that involvement and of its impact.

Department of Health, GOV UK, [The NHS Constitution³⁶](#), 26 March 2013:

Sets out the NHS Values, including a commitment to quality of care, and places responsibilities upon patients and the public to give feedback about NHS services:

“Please give feedback – both positive and negative – about your experiences and the treatment and care you have received, including any adverse reactions you may have had. You can often provide feedback anonymously and giving feedback will not affect adversely your care or how you are treated. If a family member or someone you are a carer for is a patient and unable to provide feedback, you are encouraged to give feedback about their experiences on their behalf. Feedback will help to improve NHS services for all.”

The NHS Constitution

33. Guidance for providers on meeting the Health and Social Care Act 2008 (Regulated Activities) Regulations: <http://www.cqc.org.uk/content/regulation-17-good-governance>

34. Health and Social Care Act, 2012: <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

35. NHS Standard Contract: <https://www.england.nhs.uk/wp-content/uploads/2016/04/2-nhs-ll-length-1617-scs-apr16.pdf>

36. The NHS Constitution: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england>

Department of Health, GOV UK, *Liberating the NHS: No decision about me without me*³⁷ – Government response, 13 December 2012:

2.4 We consider that greater patient involvement and greater patient choice are all part of the same goal: to ensure that “no decision about me, without me” becomes the norm. This would be achieved through greater patient involvement in decisions about their care where patient involvement may mean better shared decision making, better care planning, or more support for self-care. This would also be achieved through greater patient choice. We believe everyone should have choice as a patient; choice of who provides care, of when and where care is provided, and a choice of clinical team.

Department of Health, GOV UK, 2013/14 *Choice Framework*³⁸, December 2012:

Patients’ right to choose where to be treated.

Patients and Information Directorate, NHS England, *Transforming Participation in Health and Care, ‘The NHS belongs to us all’*³⁹, Publications Gateway Reference No. 00381, September 2013:

Engaging and involving communities in the planning, design and delivery of health and care services for joined-up, co-ordinated and efficient services that are more responsive to local community needs. Public participation to build partnerships with communities and identify areas for service improvement.

Monitor, GOV UK, *Well-led framework for governance reviews*⁴⁰, April 2015:

Q8 Does the board actively engage patients, staff, governors and other key stakeholders on quality, operational and financial performance?

- A full and diverse range of people’s views and concerns are encouraged, heard and acted upon. Information on people’s experience is reported and reviewed alongside other performance data
- The service proactively engages and involves all staff and assures that the voices of all staff are heard and acted on

- Staff actively raise concerns and those who do (including external whistleblowers) are supported. Concerns are investigated in a sensitive and confidential manner, and lessons are shared and acted upon
- The service is transparent, collaborative and open with all relevant stakeholders about performance

NHS England, *Five Year Forward View*⁴¹, October 2014:

Engaging communities

“We need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services. Programmes like NHS Citizen, point the way, but we also commit to four further actions to build on the energy and compassion that exists in communities across England. These are:

- Better support for carers;
- Creating new options for health-related volunteering;
- Designing easier ways for voluntary organisations to work alongside the NHS; and
- Using the role of the NHS as an employer to achieve wider health goals.”

Professor Sir Bruce Keogh, *Review into the quality of care and treatment provided by 14 hospital Trusts in England: overview report*⁴², July 2013:

In the wake of the Mid Staffordshire NHS Foundation Trust Hospital inquiry, the Prime Minister asked Professor Sir Bruce Keogh to review the quality of care and treatment provided by hospital Trusts that were persistent outliers on mortality indicators. His publication set out common themes or barriers to delivering high quality care and stated: “how important and how simple it can be to genuinely listen to the views of patients and staff and engage them in how to improve services”.

37. Liberating the NHS: No decision about me without me: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf

38. Department of Health Choice Framework: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england>

39. Transforming Participation in Health and Care, ‘The NHS belongs to us all’: <http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf>

40. Well-led framework for governance reviews: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422057/Well-led_framework_April_2015.pdf

41. Five Year Forward View: <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

42. Review into the quality of care and treatment provided by 14 hospital Trusts in England: overview report: <http://www.nhs.uk/nhsengland/bruce-keogh-review/documents/outcomes/keogh-review-final-report.pdf>

Appendix 2 – Promotional poster

An example poster inviting patients and the public to join quality improvement initiatives:

Would you like to help shape your NHS?

**WHY NOT GET INVOLVED TO
IMPROVE THE QUALITY OF SERVICES?
WE VALUE YOUR INPUT & OPINIONS**

- Participate in service improvement projects
- Training provided
- No past experience required
- Voluntary – but travel expenses paid
- Commit as little or as much time as you wish
- Great for your CV!



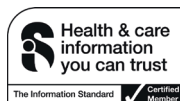
**WE HOPE TO HEAR
FROM YOU!**

If you are interested, please contact us:

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Email: patientandpublic.involvement@sunnyton.nhs.uk

HQIP service user network



Further information is available at: www.hqip.org.uk

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