

Developing a patient and public involvement panel for quality improvement





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With special thanks to HQIP Service User Network

Version history:

Replaces "A guide to developing a patient panel for clinical audit"

Updated August 2017

Next review:

November 2020

HQIP
service user network

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1 Introduction to the guide

Patients and the public offer a unique voice to service development, identifying required improvements and inefficiencies first hand as experts by experience. One way to engage this valuable resource is to set up a patient and public involvement (PPI) panel to help drive effective quality improvement projects. PPI means ongoing, strategic-level partnership-working throughout project life cycles, and, ultimately, fully patient-led activity.

“Quality improvements achieved through the patient panel have been considerable - we just wish we’d set it up sooner!”

Sally Allen, Clinical governance manager
The Shrewsbury and Telford Hospital NHS Trust

PPI offers the timely opportunity for lay representatives to provide input as advocates for patients, contributing to an annual quality improvement programme through co-participation, working in partnership with healthcare organisations on individual quality improvement projects such as clinical audits, and disseminating findings in order to share good practice.

This guide is designed to help healthcare organisations involve patients, service users, carers, and members of the public in all aspects of quality improvement, through the development and implementation of a PPI panel.

Throughout this guide, the term ‘PPI’ covers the inclusion of those who access health and/or care services, carers, and members of the public, in quality improvement initiatives.

*HQIP's guide to patient and public involvement in quality improvement*⁴ describes a number of other ways in which involvement might take place to improve the quality of services.



This visual captures discussions at a co-participation event at Kingston Hospital NHS Foundation Trust, one of a series of events held by the London Strategic Clinical Network

1. HQIP's Guide, Patient and public involvement in quality improvement: www.hqip.org.uk/resources/developing-patient-panels

1.1 Seven principles of involvement

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 and the public 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*² in line with the *National Involvement Standards*³ (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 formats that are easily understood

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

1.2 Who is this guide for?

This guide is intended to be useful to patients, the public, and staff working in quality improvement in NHS healthcare provider organisations, though all healthcare staff should find the guide useful as they become involved in quality improvement work.

Although the guide has been written for use in healthcare, many of its recommendations can be adapted for use in social care settings, to help care provider organisations involve service users, carers, family members and other advocates in the quality improvement process. See also our guides in *Social Care and Quality Improvement*.



2. 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: www.nationalvoices.org.uk

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

1.3 Why PPI in quality improvement?

A number of government papers highlight the need for a more patient-focused NHS that involves the public in how the NHS is run. From the establishment of community health councils in 1974 to organisations such as [Healthwatch England](#),⁴ [Community Health Councils](#)⁵ in Wales, [The Scottish Health Council](#),⁶ and [The Patient Client Council](#)⁷ in Northern Ireland, along with the [NHS Constitution](#)⁸ published in 2013, the NHS continually strives for structured ways to involve patients and the public.

Internationally, PPI is seen to enhance healthcare as a benchmark of quality services that are oriented, planned and delivered to meet patient needs.



Involvement of patients and the public in service development as experts by experience provides a different perspective from that of clinicians and managers. The patient has an insightful subjective viewpoint based on actual experience in healthcare, and members of the public as patient representatives are more attuned to patient interests than the organisational agenda on which staff are naturally focused. Involving patients and the public in quality improvement initiatives often leads to the study of areas of clinical practice not previously considered, which are essential to patient wellbeing.

To be fully effective, quality improvement teams must ensure that they respond to the needs of patients. Involving patients and the public throughout the quality improvement cycle provides insight into their preferences, a fresh perspective on processes, and helps in disseminating results and promoting change.

On a practical level, a PPI panel can shape and validate the local quality improvement and clinical audit programme, assist with data collection, for example, through interviews, surveys and questionnaires, and with analysis and reporting, and help produce the associated communication programme. There are a variety of [case studies](#)⁹ on HQIP's website offering excellent examples of PPI in quality improvement.

“The ideas for audit, in the form of the precise audit questions, standards and outcomes that are being used, need to reflect patient views about primacy of topics and outcomes as well as the views of clinicians and managers ... the dissemination and communication of reports should be to and by patients, along with their involvement in ideas for service improvement...it is the patient group who should lead and receive the report just as much as the healthcare provider staff and management.”

Burgess, R. (ed)

NEW Principles of Best Practice in Clinical Audit (HQIP, 2011)

4. Healthwatch England are the consumer champion for health and social care in England: www.healthwatch.co.uk

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

6. The Scottish Health Council promote patient focus and public involvement in the NHS in Scotland: www.scottishhealthcouncil.org

7. The Patient and Client Council provide an independent voice for people in Northern Ireland: www.patientclientcouncil.hscni.net

8. The NHS Constitution establishes the principles and values of the NHS in England: www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

9. PPI case studies can be found here: www.hqip.org.uk/search/?searchType=phrase&keywords=case+studies&searchSubmit=SEARCH&refData_1=&refData_2=&refData_3=&siid=14

1.4 How is the guide intended to help?

HQIP believes one of the ways to achieve effective and meaningful PPI for optimal quality improvement is to establish a PPI panel, to enhance collaboration with patients and the public through structured co-design, co-production and service user-led activity.

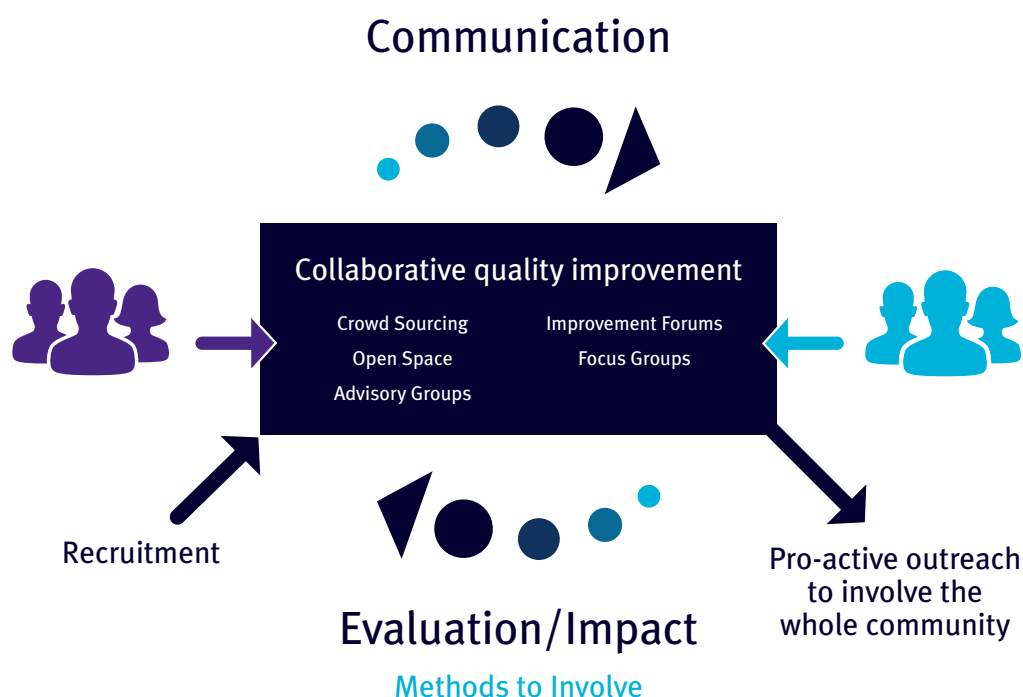
The term ‘patient and public involvement panel’, or ‘PPI panel’, is used in this guide to describe a group of people with a specific role and remit to influence and improve quality improvement practice from a patient or carer perspective. A range of other terms are used in practice, such as ‘patient participation group’, or ‘patient forum’, but in essence the role, remit and set up of such groups is the same. This is a step-by-step guide for you to follow to develop a PPI panel that is valuable to and benefits your patients, carers, volunteers, quality improvement programme and organisation.

Additional tools to help you in this process can be found on the [HQIP website](https://www.hqip.org.uk),¹⁰ and links to further reading can be found at the end of this guide.

1.5 Leadership

Effective leadership is a key driving force in the success of any project, and the development of a sustainable patient and public involvement panel is no exception. Whether a committed executive sponsor, organisational PPI champion, quality governance lead, or PPI panel Chair, strong leadership is necessary to bring patients, the public and staff together for collaborative quality improvement.

Selection and appointment of an effective leader, with executive support, is therefore essential in order to set up a patient and public involvement panel for quality improvement. Responsibility for the leadership of a patient and public involvement panel does not just rest with the appointed Chair and, particularly through the early days of development of a panel and associated projects, the executive sponsor will need to support patient and public representatives and staff in developing the knowledge, skills and confidence they need for effective dialogue and interaction. Ultimately, once established, and with training and experience, the aim should be for the panel, and the work of the panel, to be led by patients or members of the public, as seen in the case studies throughout this guide.



Collaboration between patients, the public and staff is essential for optimal quality improvement

¹⁰. HQIP website: www.hqip.org.uk/resources/developing-clinical-audit-patient-panels

2 Involvement

Involvement empowers patients to a point where they can take part in strategic decision-making from the very start of an improvement project, developing the local quality improvement programme, and leading on specific quality improvement projects.

2.1 Strategic involvement – committee membership

Within the healthcare organisation governance structure there is usually a committee with responsibility for developing quality improvement strategies, policies, and the local quality

improvement programme and reports. This group should also have the remit for ensuring that priority projects involve patients and the public and demonstrate improvements in clinical care, patient experience and service provision.

Having a PPI panel representative on such a committee will help ensure that a patient perspective is included within all key decision-making.

2.2 Quality improvement

HQIP's quality improvement cycle includes four main stages:



HQIP's quality improvement cycle

In Stage 1 of the quality improvement cycle (Preparation and Planning), the panel can:

- Introduce topic areas and ideas
- Help teams to decide on priority areas
- Contribute ideas to the methodology
- Agree the standards to be used
- Set up a PPI Impact Assessment to assess the impact of involvement (see [Section 3](#) of this guide)

The panel can give a quality improvement project more validity, for example, when explaining the project to other patients, gaining approval from the Board, and securing funding from senior management.

Before embarking on Stage 2 of a quality improvement project (Measuring Performance), the panel and staff will need to agree the level of involvement they are prepared, and required, to dedicate to the project, and the resources they will need, for example, office space, computer access and printers. This is to ensure that any barriers to project completion are detected and addressed prior to data collection.

When patients need to be interviewed, you may find they speak more openly with a panel member than with Trust staff or clinicians.

During Stage 3 of the quality improvement project (Implementing Change), and Stage 4 (Sustaining Improvement), the PPI panel can contribute to how the results are collated and presented and provide a patient perspective on what the results say about a service. Often a patient view of what is an important finding will differ from that of a clinician.

In the interests of sharing the learning, it is important to feed back internally and externally how the Trust has fared in the quality improvement project. A panel member can help present the results to senior management, helping to foster the staff engagement that is needed to implement change. To support any panel members who would like to be ‘champions of change’, consider training needs (such as public speaking, assertiveness) or using a buddy system (partnering a panel member with a member of the quality improvement team, or a clinician).

The case study on the following page is an example of a survey that was fully led by a PPI panel:

Case study:

Patient panel led survey – Intra-vitreous injection

This submission demonstrates:

- Competence of lay auditors
- Reduced clinical bias of lay auditors
- Effectiveness of lay auditors

July 2017

Wrightington, Wigan and Leigh NHS Foundation Trust
www.wwl.nhs.uk

Summary

The group comprises four lay auditors at Wrightington, Wigan and Leigh NHS Foundation Trust who have undergone training in clinical audit, along with training and formal preparation as volunteers for the Trust, which included signing a confidentiality agreement.

They bring an impartial, objective, patient experience focused resource to the Trust, and often identify issues staff are too busy or too familiar with the service to notice for themselves.

Aims

- An impartial survey of intra-vitreous injection treatment
- A survey reflective of different days and staff at the intra-vitreous injection clinic
- A significant enough number of survey participants
- Independent data collection, analysis and presentation

Objectives

- Surveys were to be carried out by lay auditors for their impartiality and independent point of view
- Surveys were to take place on different dates, including weekends, spanning a period long enough to enable review of a wide range of scenarios, related to the different systems and staff in place on different days, and the resulting changes to patient experience
- A significant number of survey questionnaires were to be completed, to produce data robust enough from which to draw conclusions
- Data would be collected, analysed and shared by the lay auditors for their impartiality and independent point of view, including presentation at a departmental meeting for discussion and agreement of actions to be taken as a result of findings

Background

The group were asked to survey patients who attended on a regular basis for injections into their eyes (intra-vitreous injection), to identify any aspects of service delivery that might be improved.

Lay auditors were used to minimise any bias that might result if clinical staff were to ask the questions.

The survey was undertaken using a questionnaire that had been designed and agreed with the lay auditors. It was discussed with patients after their treatment was completed, whereby patients were asked if they would agree to complete the survey, but were advised that it was not compulsory.

Approach

- Surveys were carried out on Mondays in January, February and March 2015, and on one Saturday in March
- 50 survey questionnaires were completed
- Survey results were collated and analysed by the lay auditors, who gave a presentation in July 2015
- Following on from this a number of action points were identified to either reinforce the delivery of the current pathway for intra-vitreous injection, or to make minor improvements
- The potential for a re-audit in six months time was seen as beneficial

Challenges

Certain survey outcomes were presumed to be likely – for example; an anticipated area of concern for patients was the experience of pain during the injection itself. However, the lay auditors found that 88% of patients indicated that they felt no pain at all. New patients, who were more likely to experience pain also indicated that any pain was bearable and short-lived. All patients felt they had enough information about their condition; 4% felt it was too much.

Outcomes

96% of patients were completely happy with the service provided, for such reasons as:

- “The staff were brilliant, always pleasant, not usually any wait, nothing is too much trouble.”
- “The one-stop appointment was a pleasant surprise.”

However, other views for attention included:

- “I found it disconcerting once when the doctor did not say anything to me.”
- “When someone flinched the surgeon blamed the patient.”

Conclusion

The survey demonstrated overall satisfaction levels with intra-vitreous injections were very high. Pain during the injection did not appear to be a problem; anaesthetic eye drops were effective. Many compliments were received about the technique that two staff members had with the injections,

which could be shared with other staff. However, some specific improvements were recommended:

- The ability to make the next appointment on leaving the clinic
- Knowing when Saturday clinics are held, as these are convenient for many patients with their travel and work commitments
- The ability to combine the injection with a wider appointment to review eye condition was greatly appreciated, but people would like to know in advance so that they can make appropriate travel arrangements

The survey results and subsequent implementation of an action plan to reinforce effective practice and make improvements to the quality of care have proven to be worthwhile for patients and staff alike.

Feedback

“As lay auditors we see what clinicians and other staff don’t necessarily see, because we have no organisational agenda. Patients sometimes tell us things they wouldn’t feel comfortable sharing with staff, particularly clinical staff. Our perspective is independent and focused upon improving the patient experience.”

Adrian Hardy, Lay auditor

Update 2017

The department had not invited a re-audit prior to July 2017, but one is anticipated by the year end. The Lay Auditors have been involved in other reviews within the Trust in the intervening period.

Contact details

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3 PPI impact and evaluation

PPI in quality improvement (QI) should be meaningful and therefore make a positive difference to the delivery of a QI project. It should result in better understanding of areas primed for service improvement and also enhance the health and wellbeing of patients, people who use services as well as their carers. At a macro level it could also have an impact on, members of the public who have not yet used the service or perhaps have used it some time ago.

Becoming involved in effective quality improvement projects can also positively impact those taking part, broadening their skills and increasing their confidence through participation and membership of teams that review, plan, implement and lead to change for the better.

The National Survivor User Network (NSUN)¹¹ hosts the National Involvement Partnership (NIP)¹² project, funded by the Department of Health. The project aims to develop national standards for the involvement of service users in mental health and social care services. This includes establishing a national infrastructure for involvement to: ‘hard-wire’ the service user and carer voice and experience into the planning, delivery and evaluation of health and care services; share good practice; centralise resources; strengthen existing networks; and promote user and carer leadership, realising the vision ‘nothing about us without us’.

It aims to bring together all of the knowledge and expertise about service user and carer involvement built up over the last few decades. In line with their National Involvement Standards,¹³ the following six questions should be asked to assess the impact of each involvement project, with service users providing input into responses:

1. What were the original plans, priorities, assumptions and intended outcomes of the involvement activity?
2. What were the recommendations made by those involved and why?
3. What changes have been made to the project/ service/organisation as a result of the involvement and recommendations? (This can be monitored by continuous recording throughout a project of qualitative and quantitative impact as well as appropriate assessment at the end which can isolate and associate outcomes directly or indirectly to PPI)
4. How did everyone (PPI and QI project team) feel about the process of involvement? Include staff, those involved, other stakeholders, and this can be done through set questions?
5. What outcomes have been observed by all involved in the project?
6. What improvements can be made in the process?

11. The National Survivor User Network (NSUN) for mental health: www.nsun.org.uk

12. The National Involvement Partnership (NIP) strengthens involvement in the planning, delivery and evaluation of the services and support we use for our mental health and wellbeing needs: www.nsun.org.uk/about-us/our-work/national-involvement-partnership

13. 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: www.nsun.org.uk/assets/downloadableFiles/4pi-ni-standards-for-web.pdf

4 Approval

4.1 Gaining approval

To enable a Board to be assured that it is fully engaged with PPI in quality improvement, the healthcare organisation's approach should be laid out within an approved Quality Improvement Strategy and [Clinical Audit Policy](#)¹⁴ or similar. These documents should cover all organisational considerations for involving members of the public and patients, including their training, arrangements for volunteer contracts, and signing a [confidentiality agreement](#).¹⁵

It is also important to ensure that steps taken are in accordance with the organisation's Patient and Public Involvement Policy, or similar. Having the appropriate and agreed organisational processes in place can prove essential to support any business case for additional funding or resources relating to PPI activity.

Below is a list of questions that you may wish to ask your Board around their level of engagement with PPI activity.

Key question:	Acceptable answer:	Insufficient answer:
1. What steps are we taking to involve patients and the public in quality improvement?	We are working with the PPI Lead in our organisation and with the local Healthwatch team to put together a quality improvement PPI panel. Our aim is to work closely with the PPI panel when choosing topics for quality improvement, including clinical audit, and to develop these in consultation with them.	We send out a survey once a year and put together a report.
2. What steps has our organisation taken to connect with the local Healthwatch team or Patient Participation Group (PPG), ¹⁶ or similar?	We liaise with the local authority and ensure there is communication with the local Healthwatch team. We add a notice to our monthly e-bulletin to invite members of Healthwatch to join the quality improvement PPI panel, and we communicate our reports to them.	We send a member of the clinical audit team to attend Healthwatch meetings.
3. Do we have a comprehensive programme available to support PPI in quality improvement?	We have a PPI Strategy that is available on our website and shared with each member of staff. Our Quality Improvement Strategy forms the basis for the quality improvement and clinical audit programme. It is developed in partnership with the quality improvement PPI panel along with the programme, and reviewed annually and highlighted as a priority programme.	There is a PPI Strategy for the whole organisation, which we use when conducting a patient survey.
4. Do we have a system in place to monitor the level of PPI in our quality improvement programme?	We carry out an annual review of our quality improvement programme to ensure we are meeting best practice criteria. PPI features as a main indicator of best practice in quality improvement. The PPI panel for quality improvement has received training, is involved in the development of our quality improvement programme, and is enabled to monitor our work, ensuring PPI at all stages.	Each quality improvement initiative has a tick box form including a question about whether patients have been involved in the process.
5. How do we measure the impact and success of PPI in our quality improvement programme?	As part of the annual review the PPI panel evaluates the re-audit results of quality improvement projects they have been involved in. This evaluation forms part of the annual report and includes an action plan for further improvement.	We review quality improvement project registration forms and see what percentage of our quality improvement projects have the PPI box ticked.

14. HQIP's template clinical audit strategy and policy: www.hqip.org.uk/template-policy-strategy

15. Example confidentiality agreement template: www.hqip.org.uk/resources/developing-clinical-audit-patient-panels

16. PPG's are linked to Clinical Commissioning Groups. See link for local CCG: www.england.nhs.uk/ccg-details

4.2 Business plan

When writing a business plan to fund PPI activity, you may need to consider the points below:

4.2.1 Consult colleagues about similar projects

It is useful to meet with any PPI leads/teams in your organisation that have already worked with volunteers, look at initiatives in place and work together to improve processes. There may be other teams within the organisation who would like to/are making plans to work with volunteers; your business plan can link to this, illustrating areas of overlap, and how increasing PPI activity can have a positive impact upon other areas of the organisation.

4.2.2 Carefully consider your budget requirements

You will need to source a budget for the PPI panel. Catering should be provided, and considerations include dietary requirements. If expenses policies do not cover such scenarios, provision should be made. In order to keep travel costs down, include information such as buying train tickets as early as possible, only travelling standard class and limiting refreshment purchases to £10 (subsistence allowance may only be necessary for national meetings). You can help by timing meetings for the middle of the day and avoid peak time travel costs. Arrangements should be made for those who may require taxis, and those with particular access needs. All expenses should be covered and paid promptly for those volunteering their time. For those patients and members of the public who can't pay for travel up front, organisations should, where possible, book tickets in advance. These reimbursement arrangements should be shared during recruitment drives to encourage uptake, and set out within the organisational expenses policy. Provision for one-off payments for considerable input to significant pieces of work may also be included. See HQIP's own [Service User Network Expenses Policy](#)¹⁷ as a reference.

4.2.3 Plan staffing resources

Include within the business plan the level of support required in terms of staff. The set up period may require more input from members of the quality improvement team. As the panel becomes established and secure in its remit, less support should be required.

4.2.4 Use established resources to source volunteers

There are likely to be established patient/service user groups in your area, such as your local [Healthwatch](#)¹⁸ branch or similar, who may have a list of contacts: people who are willing volunteers and are interested in quality improvement. Other organisations such as cancer networks, or charities such as [Age UK](#),¹⁹ provide opportunities for promotion through newsletters and email bulletins. While it is important to reach out to as wide a group as possible, using established links will help get the ball rolling.

4.2.5 Ensure your recruitment process does not discriminate

Carry out an Equality Impact Assessment as this will help to ensure that setting up the panel does not discriminate against any disadvantaged or vulnerable persons. It's important to proactively outreach in your community and use different methods to engage your patients and public.

4.2.6 Complete a PPI Impact Assessment

Set up a PPI Impact Assessment, by considering the five questions listed within [Section 3](#) of this guide, to be completed:

- Through the lifecycle of the PPI panel development project
- For each individual project thereafter in which the PPI panel are involved

17. HQIP's internal and external expense policy: www.hqip.org.uk/about-us/expenses-and-complaints-policy

18. Healthwatch England are the consumer champion for health and social care in England: www.healthwatch.co.uk

19. Age UK is the country's largest charity dedicated to helping everyone make the most of later life: www.ageuk.org.uk

4.3 Information governance and ethics

Healthcare organisations must comply with the law and good practice when involving patients and the public in quality improvement studies. It is therefore essential to consult your information governance lead, to ensure compliance and to carry out a privacy impact risk assessment. Moreover, you should always seek the approval of your Caldicott Guardian and senior information risk officer (SIRO) for such studies.

Personal confidential data – including a patient’s health record – can only be disclosed under certain specific circumstances. Patients must give consent to their personal confidential data being disclosed to anyone other than:

- Those who provide direct care
- Employees of the care provider accessing that information as part of their designated role

It should be noted that agreements such as honorary contracts between organisations and panel members (even with confidentiality clauses) cannot provide a legal basis for panel member access to health and other confidential information.²⁰ The only legal basis for that is explicit consent.

Patient panel members should not be involved in collecting data from patient health records. Data collection represents just one step in the entire quality improvement cycle and patients and the public can contribute to the topic selection, planning and design of projects, the analysis and review of results, and the planning and implementation of improvements, without the need to see the personal confidential information of individual patients through health record review.

When patient panel members invite other patients to give their views on their treatment and experience it should be made clear to those patients that they are under no pressure to participate, and that participation is on a purely voluntary basis and they can withdraw at any time. Where patient panel members collect data through surveys or interviews, any patient, service user, carer or staff member completing the survey or undergoing interview should be:

- Informed of the content of the survey or interview
- Informed of the purpose of the study
- Invited to take part in the study, if they would like to do so
- Asked to consent to their involvement, and to the sharing of their anonymised responses and how their data will be used
- Allowed the opportunity to ask questions

For effective healthcare quality improvement it is important to involve and gather the views of a range of service users, including those from vulnerable groups. Consent for the involvement of a child (aged under 16) as a panel member or as a patient must be obtained from a person with parental responsibility. In addition, adults who lack the mental capacity to decide to be involved as a panel member or as a patient, should only be involved in liaison with their advocate, in line with the [Mental Capacity Act](#).²¹

All involved in healthcare quality improvement studies should undergo information governance training, receive appropriate security clearance, and read and sign a confidentiality agreement. Further associated information can be found in HQIP’s [Information Governance Guide](#),²² which is available on the HQIP website.

Legal considerations of which you must be aware when data is collected, for example, through interviews or other collaborative service development work, are outlined at [Appendix 1](#) of this guide – it should be noted however that legislation changes over time.

20. See www.igt.hscic.gov.uk/Resources/Honorary%20contracts.pdf

21. Mental Capacity Act 2005: www.legislation.gov.uk/ukpga/2005/9/contents

22. www.hqip.org.uk/resources/information-governance-in-local-quality-improvement/

4.4 Risk assessment

In line with your organisation's Risk Management Strategy, you should undertake an assessment to cover the considerations outlined below, though if you have not undertaken risk assessment training it is advisable to discuss this with your organisational risk manager.

Some risks may only be relevant during some quality improvement projects, therefore a risk assessment is needed for each project and should be carried out at a practical level, involving PPI panel members, rather than as a stand-alone paper based exercise. You will also need to involve your organisational information governance lead, who will advise on how to meet the needs of the [Data Protection Act 1998](#),²³ [Caldicott Principles](#),²⁴ and the common law of confidentiality. You should also ask your information governance lead to help you carry out a privacy impact assessment as part of your wider risk assessment.

When you carry out your quality improvement study risk assessment, ensure that:

- Your organisation complies with all information governance legislation
- Your organisation complies with all health and safety policies

- You are aware of and have made provision for patients' needs, for example, wheelchair access and lift availability, chairs with arms, and accessible toilets
- Where the PPI panel becomes involved in any data collection, for example, by interviewing patients, risks need to be considered, discussed and managed through an agreed organisational approach, including:
 - Steps to take if a panel member accesses or is given patient information outside the scope of their involvement
 - Steps to take if a panel member discovers someone they know when they are interviewing, or discovers information regarding someone they know
 - Steps to take if a panel member inadvertently divulges patient information to others

Procedures should be in place to ensure that panel members will immediately stop work if they become aware that data relates to someone they know, so that a different panel member can complete the exercise.

Organisations should ensure that they have insurance to cover the risks of panel member involvement, including information security risks.

23. The Data Protection Act 1998: www.legislation.gov.uk/ukpga/1998/29/contents

24. Department of Health, 2013. Information: To Share or not to Share, Government Response to the Caldicott Review: www.gov.uk/government/uploads/system/uploads/attachment_data/file/251750/9731-2901141-TSO-Caldicott-Government_Response_ACCESSIBLE.PDF

5 Recruiting patients/public/volunteers/carers/people who use services

When writing the business plan you may have already come across established patient groups and made contacts through speaking with the organisational PPI team or a patient experience lead. These are good places to start. Other approaches include sending out invitations to the local [Healthwatch](#)²⁵ branch or similar, and to voluntary sector network groups, which can be done through channels such as email bulletins, newsletters, magazines, website pages and social media. Other options include displaying posters in waiting rooms, surgeries and community centres. Contact your organisation's communications manager for local ideas.

You may like to organise an open day where you can provide more details about what quality improvement is, and how a PPI panel can be involved, inviting quality improvement leads along to present specific projects to share how they have resulted in improved services.

Catering should be provided at such events and travel expenses should be covered and paid promptly for those volunteering their time. Expense reimbursement arrangements should be highlighted during recruitment to encourage uptake.

Some organisations ask potential members to complete application forms and go through an interview process, but you may decide that this is not necessary.

Everyone who signs up to the panel should receive training to cover any gaps in their knowledge (see [Section 6](#) of this guide).

Here follows a downloadable example of a [patient and public involvement panel poster](#)²⁶ invitation, which can be adapted for local use:

WOULD YOU LIKE TO HELP SHAPE YOUR NHS?

Why not get involved to improve the quality of services? We value your input and 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!

If you are interested, please contact us:

Tel
insert phone number here

Email
insert email address here



HQIP's downloadable example of a poster inviting PPI, for your local adaptation

25. Healthwatch England are the consumer champion for health and social care in England: www.healthwatch.co.uk

26. HQIP's downloadable example of a poster inviting PPI, for your local adaptation: www.hqip.org.uk/resources/developing-patient-panels

6 Panel training, education and preparation

PPI panel training, education and preparation will be required as follows:

- Organisational induction – as per local induction and volunteer policies, to include information governance training
- Local induction – to include meeting the quality improvement team and relevant clinical leads, awareness of key policies, safety and security, layout of site(s), building(s) and office space
- Ensure PPI panel members undergo any relevant, mandatory organisational training, including ongoing information governance training
- Ensure PPI panel members undergo ongoing training and support as required, particularly where techniques are new to those involved
- Ensure PPI panel members are registered as volunteers in your organisation
- Your organisation may require a contract of service to be signed
- Your organisation may carry out a Disclosure and Barring Service (DBS) check for any previous convictions; NHS Employers provide information on the pre-engagement checks required for all types of NHS staff and volunteers, and some Trusts use the Research Passport of the NHS National Institute for Health and Research (NIHR) for PPI panel pre-engagement checks²⁷

Further examples of training and support:

- [*Confidentiality agreement template example*](#)²⁸
- [*HQIP's Guide to quality improvement methods*](#)²⁹
- [*HQIP's e-learning package introducing patients and the public to quality improvement*](#)³⁰
- Much more is available on HQIP's [*website*](#)³¹

27. NHS National Institute for Health and Research (NIHR) Research passports: www.nihr.ac.uk/about-us/CCF/policy-and-standards/research-passports.htm

28. Example confidentiality agreement template: www.hqip.org.uk/resources/developing-patient-panels

29. HQIP's Guide to quality improvement methods: www.hqip.org.uk/resources/guide-to-quality-improvement-methods

30. HQIP's e-learning package for patients and the public: www.hqip.org.uk/resources/introduction-to-quality-improvement-for-patients-and-public/

31. HQIP's website: www.hqip.org.uk

Case study:

Developing a clinical audit patient panel – revisited

This submission demonstrates:

- Evolution of a patient panel to independence
- Successful patient-led quality improvement
- Skills of lay members

July 2017

Shrewsbury and Telford Hospital NHS Trust

www.sath.nhs.uk

Summary

This case study revisits Shrewsbury and Telford Hospitals NHS Trust, who developed a patient panel throughout 2013 after attending a HQIP workshop. They won the PPI and clinical audit award at the HQIP 2014 conference and this case study reviews their progress since then.

The patient panel is now established, and is patient-led, with admin support from the team, and guidance available when requested. The Panel have completed one full audit project, focussing on discharge. This included completion of the audit cycle by carrying out the audit, recommending changes and re-auditing. They have also carried out other projects of their own and supported Trust audit projects.

The Trust is grateful for the impact of their work to improve quality.

The panel completed their first audit project during 2014/15, focussing on patient discharge. Panel members were involved in all aspects of the project from designing the audit aims and criteria, through to data analysis and presentation of results at Trust committees. At the end of 2015, following implementation of recommendations by the Trust, the panel re-audited showing improvements.

Aims

- To coach the panel to independence
- To reap the rewards of patient-led improvement
- To enable panel members to share their individual skills and expertise

Objectives

- To support and guide the patient panel to be able to take forward their own quality improvement agenda and work plan
- To enable the patient panel to undertake their own audit projects independently, from start to finish
- To discover, understand and utilise the range of skills of the panel

Approach

The patient panel carried out an audit of the Trust discharge process independently. They:

- Designed the question set
- Told wards they were coming along
- Sat with patients and explained who they were and what they were doing
- Asked patients to complete their questionnaires on the discharge process

Background

The clinical governance manager at the hospital Trust initially wrote a paper outlining the proposal, along with a patient and public involvement policy, for consideration by the board. Following approval, the panel was set up. The clinical governance manager carried out interviews and recruited 12 members, providing training.

Four years on, as panel members have left, members of the current panel have been involved in recruiting new members.

The panel has been involved in a variety of Trust audit work, and have developed competence and confidence, in carrying out audit projects.

- Analysed the data using MS Excel
- Put the data into a Powerpoint presentation demonstrating what they did, their findings, conclusions and highlighting potential changes required
- Presented the work at Trust committees to enable discussion and the next steps to be taken

Challenges

- As they aren't licensed staff members, panel members were unable to access the Trust questionnaire design scanning equipment, so Trust staff members scanned in the questionnaire design for them, and panel members were then set up to scan completed questionnaires and gather data
- Staff needed to remember that patient panel members are unpaid volunteers, as they must be to remain independent in their advocacy for service-users

Outcomes

- The independent audit of the Trust discharge process carried out by the patient panel focused on aspects of care the Trust would not previously have considered; the Trust tended to focus more on meeting standards from the Trust policy, while the patient panel focused more on the patient experience, how things feel, and practical issues associated with discharge from hospital
- The patient panel had a great response rate for both the audit and the re-audit, better than is usually achieved. This was attributed to them being "patients talking to patients"
- The audit template developed by the patient panel was so comprehensive it is now used as a template for junior doctors, and for clinical audit training
- More members have been recruited to the panel and two current panel members took part in the interview process
- The clinical governance manager rarely needs to provide input to the work of the panel now, as they are confident to meet with Trust staff
- Following the success of the discharge audit, the panel were approached by the Therapies Team to support them in an audit. This project looking at how therapists are perceived by patients was completed and has resulted in new written patient information being produced by the Therapists to raise awareness of their role. A second project with the Therapists is now underway

- The panel has also carried out an audit of patient care in hospital, which was presented to Trust meetings and committees. Work is underway to make improvements, prior to re-auditing
- Patient panel members have been fantastic at publicising the work of the Trust, particularly when things have gone well, and one member has set up a Twitter account to share progress

Conclusion

The clinical audit patient panel has gone from strength-to-strength and are a valuable resource for ensuring the patient point of view is reflected in the services delivered by the Trust.

The speed with which the panel has become independent is testament to careful set up and training, and supporting the panel to explore its own approach. Investing time to thoroughly nurture the panel from the start has been worthwhile.

As a result of their success, the clinical governance manager is considering widening the remit of the panel to become a 'quality improvement patient panel', to be involved in quality improvement projects other than clinical audit.

The Trust is extremely thankful for the enthusiastic commitment the panel has shown in supporting the development of services, and grateful for the positive impact of the results of their work to improve quality and patient experience.

Feedback

"The patient panel runs itself – which we feel is due to the care taken through set-up, and training provided for members."

"Quality improvements achieved through the patient panel have been considerable – we just wish we'd set it up sooner!"

Sally Allen, Clinical governance manager

Contact details

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7 PPI panel responsibilities

Things to put in place could include:


- Terms of reference
- Chair and other roles (for example minute-taking)
- Meeting arrangements – how often, venue, resources required and minimum attendance

7.1 Sub-groups

Panel sub-groups can be formed at various stages, and members can be in as many groups as are useful. Different groups may focus on specific areas for quality improvement

and lead on projects (e.g. hospital menu, booking appointments, discharge planning, etc.), carrying out interviews or surveys and collecting and analysing data. Others may wish to join a specific quality improvement group as an expert by experience patient representative, or may prefer to be part of more generic organisational quality improvement groups and committees, involved in wider consultations on new topic areas and reviewing and challenging reports on quality improvement studies.

7.2 Roles and remit

- 
- ☒ **Leading on quality improvement studies**
 - ☒ **Shadowing the patient journey to identify shortfalls**
 - ☒ **Patient-led assessments of the care environment**
 - ☒ **Completion of patient satisfaction surveys**
 - ☒ **Review of patient information materials**
 - ☒ **Patient networking to share self-care strategies**
 - ☒ **Patient representation on quality improvement groups**

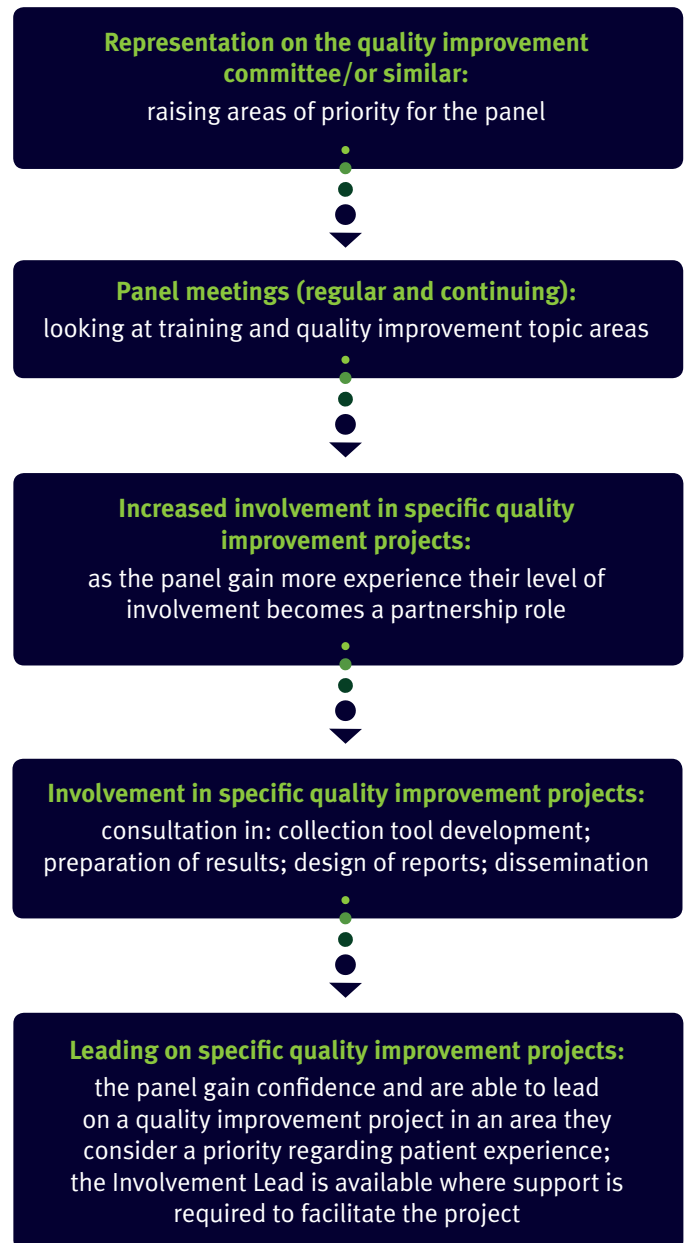
Examples of patient and public involvement in healthcare quality improvement

There are a number of ways in which patients and the public can become involved in healthcare quality improvement. When you have established a PPI panel you may wish to allow some time for the panel to gain experience and for staff to become used to the panel's involvement before embarking on more practical elements of PPI (see flowchart).

The roles and responsibilities of the panel grow over time, as illustrated by the flowchart.

If the panel reaches the point where they would like to carry out their own quality improvement study, Trusts should:

- Conduct a risk assessment
- Assess any new conflicts of interest
- Assess whether to reiterate the confidentiality agreements and [Caldicott Principles](#)³²
- Review information governance policies and ensure volunteers have copies
- Assess the training, and specific guidance the panel need, for example, protocols for health and hygiene on hospital wards, interview technique training, etc



The roles and responsibilities of the patient panel grow over time

32. Department of Health, 2013. Information: To Share or not to Share, Government Response to the Caldicott Review: www.gov.uk/government/uploads/system/uploads/attachment_data/file/251750/9731-2901141-TSO-Caldicott-Government_Response_ACCESSIBLE.PDF

8 Communication

HQIP's [guide on how to present patient-friendly clinical audit reports](#)³³ illustrates examples of user-friendly quality improvement reports, and highlights that any work being prepared for patients and the public requires their involvement throughout development. The panel can play a vital role in the preparation of these reports – they can help you to understand the information people need to hear, and ensure the reports are transparent and clear to all. As they are central to healthcare, reports should ideally include patient stories.

The panel can help publicise quality improvement project findings using a variety of methods including local newspapers, organisational bulletins, websites, roadshows, conferences, competitions, and social media, in liaison with the Trust communications team, and Board, governance, quality and clinician meetings.

The action plan at [Appendix 2](#) has been developed to help NHS organisations set up a PPI panel. It is also available as a downloadable [Excel spreadsheet](#)³⁴ on the HQIP website.



33. HQIP's Guide to patient-friendly clinical audit reports: www.hqip.org.uk/resources/how-to-develop-patient-friendly-clinical-audit-reports/

34. HQIP's Excel spreadsheet PPI panel action plan: www.hqip.org.uk/resources/developing-patient-panels

Appendix 1 Information governance legislation and principles for quality improvement studies

1. Data Protection Act

All personal identifiable data relating to a living individual is subject to the conditions of the [Data Protection Act 1998](#),³⁵ which requires that, for example, data collected for a quality improvement study through interviews, or other collaborative service development work, is:

- Accurate, relevant to the study's objectives and not excessive in quantity
- Not used for any purpose other than the study
- Not kept any longer than is necessary
- Kept secure at all times, including information held on paper, computers, discs, and memory sticks

2. Caldicott Principles

The [Caldicott Principles](#)³⁶ state that information can only be transferred for “justifiable purposes” and on a “need to know” basis. Advice should be taken from your organisational Caldicott Guardian before sharing any patient identifiable data outside of your organisation, for example, data collected as part of a quality improvement study through interviews or other collaborative service development work.

3. Duty of confidentiality

All NHS staff and volunteers are bound by a duty of confidentiality. A person not employed, with access to identifiable patient or staff data as part of a quality improvement study, for example, collected through interviews, or other collaborative service development work, must sign a confidentiality agreement issued by the organisation involved.

4. Protecting patient and staff confidentiality

Ideally, in the interests of anonymity, unique identification (ID) codes should be used to identify individual patients or staff who are the subjects of a quality improvement study. This unique ID code should be created through the application of a key, and used on all data collection sheets, spreadsheets and databases. The key to these ID codes must be kept separately in a secure place, for example, it should not be stored in the same folder as the data collection sheets. The key should be destroyed once the study is reported.

5. Patient or staff identifiable data

Always consider whether you really need to identify patients or staff. You must keep all patient and staff identifiable information arising as part of a quality improvement study secure at all times, for example, data collected through interviews, or other collaborative service development work. Security can be achieved by ensuring:

- Paper documents with patient or staff identifiable data are held in a secure environment, for example, in a locked room or drawer at your place of work
- Sensitive documents are not left on display at any time, for example, not left on a desk whilst you take a break
- Sensitive documents are not removed from your place of work
- Data is disposed of in a secure manner once the study report is written
- Electronic data is password protected
- Electronic data is stored in a secure area on a server, not on a computer hard drive

35. The Data Protection Act 1998: www.legislation.gov.uk/ukpga/1998/29/contents

36. Department of Health, 2013. Information: To Share or not to Share, Government Response to the Caldicott Review: www.gov.uk/government/uploads/system/uploads/attachment_data/file/251750/9731-2901141-TSO-Caldicott-Government_Response_ACCESSIBLE.PDF

*The General Data Protection Regulation will apply in the UK from 25 May 2018 and may make a difference to the advice provided here. Please see www.ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/ for further information'

- Data is not sent to an email address outside your place of work
- Information is deleted as soon as it is no longer essential
- Patient identifiable information is not removed from the workplace, for example, on a disc, memory stick or laptop computer
- Aside from in authorship or action-planning, patients and staff are not identifiable in reports and presentations

6. Freedom of information

The [Freedom of Information Act 2000](#)³⁷ created a public right of access to information held by public authorities, therefore anyone can apply to access information relating to quality improvement studies.

7. Ethics

All quality improvement studies must be conducted within an ethical framework. In practice this means that consideration should be given to such issues as confidentiality, and appropriate disclosure of quality improvement study results. More information around this topic can be found in [HQIP's guide to ethics, clinical audit and quality improvement](#),³⁸ which will be available on the HQIP website in May 2016.

37. Freedom of Information Act 2000: www.legislation.gov.uk/ukpga/2000/36/contents

38. HQIP's guide to ethics, clinical audit and quality improvement: www.hqip.org.uk/resources/guide-to-managing-ethical-issues-in-quality-improvement-or-clinical-audit-projects/

Appendix 2 Action plan for a PPI panel

Objective:	Action:	Responsible individual:	Potential barriers and issues:	Expected outcome:	Date by:	Monitoring:
1. APPROVAL:						
1.1 Gaining support from the budget holder	1.1.1 Prepare a business plan 1.1.2 Identify resources 1.1.3 Costs to include: <ul style="list-style-type: none"> • Promotion/recruitment • Staff time • Disclosure and Barring Service (DBS) checks • Travel/catering expenses • Training 					
1.2 Risk/Impact assessment	1.2.1 Risks to consider: <ul style="list-style-type: none"> • Staff time • Clinician concerns • Financial resources • Setting achievable targets • Reputation 1.2.2 Impacts to consider: <ul style="list-style-type: none"> • Meaningful improvements • Advocates for the organisation • Patient stories • Extra support for quality improvement (until fully functional) 					

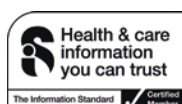
Objective:	Action:	Responsible individual:	Potential barriers and issues:	Expected outcome:	Date by:	Monitoring:
2. RECRUITMENT: Prepare information leaflets — identify areas within the organisation and in external areas where these can be displayed						
2.1 Promotion Optional – organisations might find it appropriate to hold a formal hiring process with long-standing volunteers or governors on the interview panel	2.1.1 Preparing posters for community areas including: <ul style="list-style-type: none"> • Wards • Outpatient departments • Waiting rooms (GP/dentists) • Cafes • Libraries • Information boards in supermarkets/post offices 2.1.2 Writing for newsletters and e-bulletins 2.1.3 Presentations at events including: <ul style="list-style-type: none"> • Healthwatch or similar • Local involvement networks • Community groups • Speciality groups • Diversity groups 					

Objective:	Action:	Responsible individual:	Potential barriers and issues:	Expected outcome:	Date by:	Monitoring:
2.2 Open day	2.2.1 Hold a “Recruitment day” which should involve the following: <ul style="list-style-type: none"> • A presentation on quality improvement • Present an outline of what the PPI panel might look like – it is important that volunteers ultimately decide on the aim and vision of the PPI panel • Explain why quality improvement projects should be run in partnership with a PPI panel • Give an outline of a development plan explaining the needs of your organisation • Volunteers sign up to join the panel on this day 					
3. INDUCTION:						
3.1 Volunteer status Examples of rewards can include high street vouchers, or gifts	3.1.1 Set up Disclosure and Barring Service checks 3.1.2 Organise contracts which detail: <ul style="list-style-type: none"> • Reward and recognition/expenses policies • Volunteer policy 3.1.3 ID badges are given to all panel members					

Objective:	Action:	Responsible individual:	Potential barriers and issues:	Expected outcome:	Date by:	Monitoring:
3.2 Training The free e-learning introduction to quality improvement for patients and the public on the HQIP website can be used Depending on the organisation a majority of the training could be found in-house	3.2.1 Organise as a priority: <ul style="list-style-type: none"> • Quality improvement training • Volunteer responsibilities • Information governance • Data collecting • Data security • Interview training 					
3.3 Meetings	3.3.1 A first formal meeting is organised to discuss the following: <ul style="list-style-type: none"> • Aims/Terms of reference • Further training needs • Individual goals • Organisation goals • Establishing roles • Representation at the quality improvement committee (or similar) 					

Objective:	Action:	Responsible individual:	Potential barriers and issues:	Expected outcome:	Date by:	Monitoring:
4. WORKING WITH THE PPI PANEL:						
4.1 Annual quality improvement programme For validity, minutes should be taken at all meetings, with agreements made, and project plans developed, in writing – individuals can be responsible for particular projects	4.1.1 The PPI panel is involved in development and review 4.1.2 The panel discuss their roles and responsibilities for each quality improvement project, and develop a work plan for a set time period					

Objective:	Action:	Responsible individual:	Potential barriers and issues:	Expected outcome:	Date by:	Monitoring:
5. OTHER ISSUES:						
5.1 Communication	5.1.1 Work with the PPI panel to review the overarching PPI impact assessment, interpret the results of quality improvement projects and review each associated project impact assessment					
	5.1.2 Where possible ensure the panel and clinicians can see evidence of improvements					
	5.1.3 The panel can help with ideas for communicating the results of a quality improvement project to the public					
5.2 Dissemination	5.2.1 The PPI panel can contribute ideas on how best to disseminate quality improvement reports to the public					



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

ISBN NO 978-1-907561-41-2

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November 2017. Next review date: November 2020