

Involvement for Better Data: A Guide to Action

options and approaches
for developing purpose-driven
patient and public involvement and engagement
in the work of the Data Analytics directorate
at The Health Foundation

Version 1.1

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Date	Update	Initials and title

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1. Background and structure

Introduction

This is a living document, to be edited and updated based on practice.

This guide aims to outline practical approaches to develop patient and public involvement and engagement (PPIE) in the work of the Data Analytics directorate at The Health Foundation.

The approaches should be seen as options, which may not all be applicable in the work of the directorate immediately. In outlining practical approaches to apply PPIE in the work of the directorate, this guide should be seen as a living document that may be updated to reflect practice. Options should be flexed and adapted to the needs of the directorate.

The development of this guide came out of a commissioned process to support the growth of PPIE in the Data Analytics directorate at The Health Foundation. The guide aims to support the needs of staff, while focusing on what matters to potential patient / public partners in this work. It is rooted in conversations that took place between staff and patients, and in design workshops that have developed the vision, values and outcomes for purpose-driven, meaningful PPIE.

Audience

The primary audience for this guide is the staff working in, for, and with the Data Analytics directorate at The Health Foundation. This includes the:

- in-house analytics team – who use linked data and novel analytics to monitor and assess the quality of healthcare in the UK.
- Improvement Analytics Unit - an innovative partnership between NHS England and the Health Foundation that provides robust analysis to help the NHS improve care for patients.
- Building Capability team – who support the analytical capability within the UK health and care services.

Secondary audiences may include colleagues at The Health Foundation and NHS England, organisations the Data Analytics directorate partner with, and patients, carers and the public.

Already approaching much of their work in an open source way, the directorate would like to continue to be transparent (see 'Our values' below, p.7) about their PPIE work and methods. As such, it is hoped that this guide will be made available to public audiences.

This guide is written in a way to meet the practical needs of Data Analytics staff at The Health Foundation and this should be kept in mind when it is reviewed by other audiences.

Role

This practical guide sits alongside the directorate's PPIE vision, values and commitments (as below). In January 2020 the directorate published its [Data Analytics for Better Health](#) strategy, which emphasises a broadening scope of work to help create a future where everyone's health and care benefits from analytics and data-driven technology. This guide supports practical action in PPIE towards the delivery and ongoing evolution of this strategy.

Note on approaches

This is not an exhaustive guide to all PPIE methods. Twelve methods have been selected that aim to both fit the present, and medium-term future, needs of the Data Analytics directorate and meet the potential expectations of patients and the public. Activities like [photovoice](#) or [citizens assemblies](#) have not been included at this stage, nor [shadowing](#) or [experience-based co-design](#). Nor have permutations or blended approaches been fully explored. This guide aims to build confidence in doing PPIE and emphasises simple but impactful approaches.

Structure

There are five core components to the guide, with the third containing all the individual approaches and therefore most of the content.

1. Background and structure

This outlines the role of this guide, as well as the vision, values and commitments for PPIE in Data Analytics Directorate. It concludes with some definitions for terms used throughout the guide.

2. Why do we involve and engage patients and the public?

This section focuses on why the Data Analytics directorate are working to involve and engage patients and the public, and what outcomes they specifically hope to achieve through their PPIE work. These outcomes were developed through a co-design workshop with directorate staff and patients.

3. How do we involve and engage?

This section contains 12 individual approaches, or methods, for involving or engaging patients and the public in the work of the directorate. These are written in a self-contained, 'how to', practical methodology style. The approaches and instructions are tailored to the needs and work of the Data Analytics directorate.

Individual approaches can be identified by a heading with a grey background and each is 2-3 pages.

They are grouped based on the distinct activity types:

- 3.1 Seeking advice, perspectives or insight (understand what matters to patients and the public).
- 3.2 Undertaking an assessment, selection or review process.
- 3.3 Developing or review written materials.
- 3.4 Presenting work, developing or providing training.
- 3.5 Actively involving in delivery of work - involving patients and the public as co-, or lay, researchers.

They are organised in this way to provide clear alignment with the work of the directorate. Each individual approach has the potential to target multiple outcomes (as outlined in section 2).

For the most part, these approaches are applicable in a variety of directorate work contexts. Decisions about what approach to take should be made using the related decision tree (detailed below).

Two approaches sit across the work of the directorate – a Patient & Public / Citizen Advisory Group / Board (3.1.4) and the Patient Data Citation (3.3.1).

Approaches sit across spectrums contained in theoretical models of involvement and engagement (including [Arnstein's Ladder of Citizen Participation](#)¹). Some approaches inform, listen or discuss, while others collaborate and empower. In some the degree to which the approach focuses on listening vs. collaborating will be based on the intention and confidence of directorate staff.

The individual approaches may be viewed and used independently, as well as in groups and within the context of the whole guide. This means there is some repetition across the guide to allow and encourage individual use.

¹ Arnstein, Sherry R.(1969) '[A Ladder Of Citizen Participation](http://dx.doi.org/10.1080/01944366908977225)', Journal of the American Planning. Association, 35: 4, 216 — 224. <http://dx.doi.org/10.1080/01944366908977225>

4. Frequently Asked Questions

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What is the right number of people to involve?	p.44
How do we ensure adequate representation?	p.45
What resources are required to undertake involvement and engagement work?	p.45
How do you manage expectations?	p.45
How do you build trust and relationships with patients and the public?	p.46
How do we make involvement or engagement work more accessible and inclusive?	p.46
What expenses should we cover and how do we recognise the value people bring?	p.46

5. Evaluating the impact of patient and public involvement and engagement

This section provides a brief overview of how to evaluate the impact and value of PPIE across the directorate. It is not comprehensive at this stage but does provide an outline of tools, some process metrics, a sense of the resources required and risks and mitigation.

Decision tree

A one-page decision tree, a flowchart-like structure, exists to support decision-making around which of the individual approaches might be the right fit for a specific piece of work. It is colour co-ordinated so that groups of activities (as above) in the second column align with approaches in the final column.

Definitions

This guide uses the definitions developed by [INVOLVE](#), part of the National Institute for Health Research (NIHR). The approaches outlined provide for more than involvement in research but the definitions remain useful. INVOLVE defines public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.

“When using the term ‘public’ we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.”²

INVOLVE uses the following terms to distinguish between the different activities:

- Involvement – where members of the public are actively involved in research projects and in research organisations.
- Participation – where people take part in a research study.
- Engagement – where information and knowledge about research is provided and disseminated.

This guide uses the term ‘patient / public partner’ to refer to patients, potential patients, carers and people who are involved in our work.

The term ‘communities’ is also used to refer to groups of people, across the population, who come together around a common characteristic or place. This includes community and voluntary sector organisation who support the work of communities.

The term ‘approaches’ is used to mean tools or methods that deliver desired outcomes.

² INVOLVE, NIHR (2020). What is public involvement in research? Retrieved from <https://www.invo.org.uk/posttypefaq/what-is-public-involvement-in-research/>

PPIE in Data Analytics at The Health Foundation

Our vision

Involvement for better data, [data for better health](#).

Statement of purpose

Here we outline the values that we as the Data Analytics team hold in our PPIE work, and key commitments that we make as part of those values. This is an area in which we are continually working to improve and will seek to review and update these values regularly.

Our values

We aim to work in partnership with patients and the public.

We respect experiences, skills, insights and opinions.

We work to include people who might otherwise be excluded.

We promote transparency in our activities.

Our commitments

We commit to:

PARTNERSHIP

- Ask about what matters and actively listen to your response.
- Develop skills for better partnership between team members and patients and the public.

RESPECT

- Be clear about our purpose in involving and engaging with patients and the public.
- Recognise the contribution you make to our work.

INCLUSIVITY

- Seek and value different experiences and perspectives.
- Share our work in a way that is accessible and understandable.

TRANSPARENCY

- Share what we have learnt from our work to involve and engage with patients and the public, and the impact that it has had on our work.
- Welcome constructive challenge.

2. Why do we involve and engage patients and the public?

The involvement and engagement of patients and the public in health and care services, research, and education has increased over the last decade. There has been both increasing awareness of the [value](#) it brings within the system and an increased emphasis from research commissioning bodies.

Within the work of the Data Analytics directorate, PPIE work is focused on improving research undertaken, directorate strategy and planning, efforts to shape policy and improve health, and future involvement and engagement efforts.

Underpinning all of this is an ethical, or moral, imperative and democratic principle to involve and engage those who use public services because the services should meet their needs. This recognises that our assumptions around the needs of communities may not be accurate and that it is through working in partnership that we 'improve health outcomes, facilitate the stewardship of resources, enhance prospects for justice and build public trust'.³

Moreover, involvement and engagement recognises citizens' (a distinct group within 'public') as stakeholders with rights, and responsibilities, for publicly-funded services, research and education.

Aspirational outcomes – what we hope to achieve through PPIE

Staff from the directorate and patient leaders* came together in a November 2019 co-design workshop to develop a list of desired outcomes for involvement and engagement work in the Data Analytics directorate. These four outcomes outline what we hope to achieve:

1. Improving research.
2. Supporting directorate strategy and planning to take account of what matters to the public.
3. Working to shape policy that improves health and care for communities.
4. Improving how we involve and engage patients and the public in the longer-term.

*NHS England defines patient leaders are patients, patients' family members and patients' carers who invest their time and resources to influence decision-making at a strategic level that improves service and research.⁴

The first three outcomes are ordered in the manner of widening circles of influence and control. At the centre is 'improving research', where individual directorate staff have influence through PPIE. This widens to an outcome around the strategy of the directorate, and then further to regional and national policy and planning. The final outcome is overarching and highlights that there is always room for improvement in process.

Each of these outcomes is explored in greater detail below.

1. Improving research – why we involve and engage

We involve and engage patients and the public in research undertaken by the directorate because of the potential to:

- Improve research quality and relevance.
- Provide a different perspective from that of staff.
- Build ownership of the outcome and insights.

³ Solomon, MZ. Et al (2016). *The Ethical Imperative And Moral Challenges Of Engaging Patients And The Public With Evidence*. Health Aff (Millwood). 2016 Apr;35(4):583-9. doi: 10.1377/hlthaff.2015.1392.

⁴ NHS England (2015). *Improving Experience of Care through people who use services: How patient and carer leaders can make a difference*. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2013/08/imp-exp-care.pdf>

PPIE has become a core standard in health and social care research. The National Institute for Health Research state that they expect the active involvement of the public in research they fund.

“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective.” – Professor Dame Sally C. Davies (Staley Report, 2009)

Involvement and engagement approaches may be used throughout the research process to:

- Shape overall work.
- Set priorities and outcomes.
- Develop research questions and plan research design.
- Support data collection – reflecting on what needs to be included.
- Analyse data.
- Derive new insights.
- Communicate results.
- Evaluate research.
- Award grants and funding.

2. Supporting directorate strategy and planning – why we involve and engage

Through PPIE that supports directorate strategy and planning we hope to:

- Better understand patient and public perspectives and gain ‘real world’ insights.
- Build strong partnerships with patients and communities to create greater insight.
- Be more transparent about the work undertaken by the Data Analytics directorate.
- Support a better understanding of data use, data management, and governance.

This will build confidence and trust, encourage realistic expectations to form, and lower resistance to change. It will strengthen relationships with patients and communities, which will improve involvement.

Patients and the public could be involved or engaged in:

- Governance.
- Strategic development.
- Substantive work programmes.
- Events.
- Recruitment.
- Evaluation.
- Awarding grants and funding.

3. Shaping policy that improves health and care for communities – why we involve and engage

Improving health and care for communities means understanding what communities need from health and care. While experiential aspects of service are often the focus of involvement and engagement, patients and the public also have needs around clinical outcomes and effectiveness, patient safety and value that are unexplored or delivered upon. There is a role for PPIE in ensuring that what matters to patients, carers and the public is reflected in the related outputs.

For the Data Analytics directorate, there may be specific roles around:

- Working to embed the priorities and outcomes that matter to people in developing work.
- Ensuring accessible and relevant communication of work and research.
- Disseminating work and supporting implementation of learnings.
- Shaping policy around data use, data sharing and information governance.
- Reflecting on what improving health and care means to people who use services.

4. Improving how we involve and engage – why we involve and engage

Two groups of people have practical experience of what good involvement and engagement looks like – people who lead on involvement, engagement, co-design and participatory design; and people who are involved and engaged. To improve PPIE, engaging both these groups of ‘experts’ is essential.

This may focus on:

- Designing for inclusivity and accessibility – reflecting ‘hidden’ issues and seldom-heard perspectives.
- Assessing impact and evaluating our work to involve and engage.
- Involving and engaging in a variety of ways to encourage diverse perspectives.
- Recognising the assets, skills and strengths those involved bring to this work.

Each of the individual approaches includes detail on related outcomes.

3. How do we involve and engage?

3.1 Advice, perspectives and insight

This is a group of approaches to involvement that sit across all four outcomes. They focus on asking questions and listening to responses to shape our understanding of what matters most to people.

The other groups of approaches are:

- 3.2 Assessment, selection or review.
- 3.3 Developing or reviewing written materials.
- 3.4 Presenting or training.
- 3.5 Actively involving in delivery of work.

What will these approaches help us achieve?

Understanding what matters to patients and the public in relation to a specific topic or aspect of work:

- Adds insight and knowledge and provides context to shape work.
- Supports efforts to make sure work is relevant and based on what matters to communities.
- Gives the opportunity for novel perspectives on various subjects.
- Improves the focus, quality and impact of work.
- Helps to prioritise topics to work on.

Approaches

The following guides outline four approaches:

- 3.1.1 Individual one-off involvement.
- 3.1.2 Listening events and surveys.
- 3.1.3 Interviews and focus groups.
- 3.1.4 Patient & Public / Citizen Advisory Group / Board.

Deliberative methods (including citizens' panels, senates, and assemblies) provide significant opportunity for advice and insights from the public. These would be commissioned in partnership with other organisations and, as such, are not outlined in this guide.

Example activities

- Defining research priorities, questions or outcomes.
- Answering questions about experiences or perspectives on specific topics.
- Contributing to research design, data analysis or any other part of the process.
- Mentoring staff.

Measuring impact of these approaches

Potential aims:

1. Increased understanding for staff of what matters to patients and the public and their 'real world' experiences; leading to
2. Changes in work based on the insights learned through seeking input; leading to
3. Better focus, quality and impact of work based more on real-world insights; and
4. Support funded projects to involve and engage patients and the public in their work.


Measuring staff understanding (1) and changes in work (2) will be simpler than perceptions of improved focus, quality and impact (3). Evaluation against these aims is likely best completed alongside wider evaluation of PPIE efforts across the directorate.

ADVICE, PERSPECTIVES AND INSIGHT

Guide 3.1.1 - Individual one-off patient, carer or public partner involvement

What is it?

Advisory discussions, in spoken or written form, with individual patients and the public on a one-off basis to provide perspectives on relevant aspects of work and planning. This may be an easy place to start PPIE efforts.

★★★★★	Medium complexity
£	Low resources required
	Implemented by individual staff

Related PPIE outcome(s)

1. Improving research.
2. Supporting directorate strategy and planning to take account of what matters to the public.
3. Working to shape policy that improves health and care for communities.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- Clear sense of the scope of the topic or aspect of work you want to explore.
- Some sense of the insights you would like to hear, questions you have or a hypothesis around the expected insight.

Advantages

- i. Relatively quick and simple to organize.
- ii. Discrete activity allows for clarity around expected time commitment.
- iii. Allows time and space for deeper discussion and clearer insights.

Disadvantages

- i. Usually part of a very small sample.
- ii. Not representative of wider population.
- iii. Staff may view one-off experiences and perspectives as anecdotes.

Applying in your work

Individual involvement comes in many forms, for many outcomes, and these dictate the level of complexity required. Keep 'what, why, who, where, when, how' in mind when doing this.

1. Be clear on what insights you are seeking and why – having a hypothesis around expected insight may help to clarify what you want to understand.
2. Write a list of the type(s) of people you would like to hear from – conditions/symptoms, experiences, skills, perspectives. Be clear about which groups you would prioritise, why, and how many individuals you would like to involve.
3. Think about how you might recognise the involvement contribution (see FAQs, p.46).
4. Develop materials (this might just be a paragraph in an email) that explain what insights you are seeking, expectations and how people can register their interest in being involved.
5. EITHER: Find appropriate groups and networks to advertise involvement through. Where relevant, include groups that operate outside of the 'health' space.
6. AND/OR: Contact known individuals who fit your profile and might be able and willing to be involved.
7. Follow up with interested individuals to organise written or verbal discussion. If verbal, think about what location will put the individual at ease. Ask if they have any questions about activity.

8. Prepare questions or a topic guide for written or verbal discussion. Keep open and ensure individuals have opportunity to raise anything else they would like to discuss. In verbal discussions, a semi-structured approach will allow you to flex to the conversation.
9. Ask involved individual if they have any questions for you. Provide regular opportunities for this.
10. Tell individual about next steps and ask if they would like to be kept updated on specific work.
11. Follow-up as appropriate on how work has evolved with their input.
12. Ask individuals about their experience of being involved, what worked for them and what did not. This should include ability to provide feedback anonymously.
13. Individuals may be asked to advise over the longer-term, to sit on a group of advisors, or to support with other approaches (assessment, selection or review (3.2), developing or reviewing written materials (3.3), presenting or training (3.4), or actively involving in delivery of work (3.5)).

Resources required (including time)

- ❖ 1-4hrs staff time – planning, coordination and follow-up.
- ❖ Staff time – undertake individual involvement activity (will depend on activity).
- ❖ Patient/public partner time – undertake involvement activity (as above).
- ❖ Costs – recognition for involvement and any expenses.
- ❖ Costs – minimal activity costs (e.g. refreshments).

Significant risks and mitigation

- Finding people to involve in individual activities can take some time, especially early-on in PPIE work where an established contact list does not exist.
 - Work through individuals, organisations, groups and networks that have established contact lists.
 - Keep communication simple and clear.
 - Create a GDPR-compliant list of individuals who are interested in being involved in activities.
 - Be careful with email addresses, use BCC and ensure permission is given before any sharing is done.
- May be seen as token involvement – in general or in terms of representation.
 - Best undertaken at start of, or as part of, wider PPIE efforts – mixed methods.
 - Be clear about how it is hoped collected insights will be used.

Roles and responsibilities for staff

- ☐ Individual staff – undertake applying this method in their work.

Measuring impact

Measuring the impact of individual involvement should be kept easy and focus on the experiences of the staff member and person/people who have been involved, and the usability of the insights gained through the discussion. For the person/people who have been involved, this is best done as a step in the process (see step 12 above). For staff this is likely best done as part of a follow-up survey.

Example


A common form of individual involvement is a patient / public partner sitting on a working or steering group or committee to bring their perspectives into discussions. [Many NHS England committees have patient and public voice \(PPV\) partners](#) who are active members, feeding in their insights and being part of decision-making.

ADVICE, PERSPECTIVES AND INSIGHT

Guide 3.1.2 - Listening events and surveys

What is it?

This approach covers both spoken and written forms of listening to and hearing from larger public audiences. This can form the basis of advisory work. Surveys tend to use closed questions to obtain specific answers whilst listening events tend to have open questions to stimulate discussion.

★★★★★	Medium complexity
££	Medium resources required
	Implemented by teams

Tell me more...

Listening events are an opportunity to gather patients and the public and hear from them about specific topics. These often feel like a workshop but with an emphasis on listening to discussion.

With surveys, you may choose to work with a voluntary and community sector organisation and survey their patient partners or you may work through a market research or surveying organisation to access a wider sample of people.

Related PPIE outcome(s)

1. Improving research.
2. Supporting directorate strategy and planning to take account of what matters to the public.
3. Working to shape policy that improves health and care for communities.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- A clear situation where you would like to know more from patients / public.
- Topics and or questions you want to ask about.
- Clarity around audience / people you want to hear from.
- Resources to manage the listening event or survey process.

Advantages

- i. Easy way to get advice from a larger group of people.
- ii. Potential for high value feedback, if you ask the right questions and structure well.
- iii. Survey offers the potential to access a close to representative sample.

Disadvantages

- i. Medium to high cost.
- ii. Easy to ignore feedback.
- iii. Complexity in analysing the feedback. Work is needed to synthesise the learning and bring it together with an action plan.
- iv. Complexity in managing listening events.

Applying in your work

1. Write a clear brief stating the topics, questions, and hypotheses you want to explore and the specific patient / public audience these refer to.
2. Decide whether you are going to do a listening event or a survey:
 - a. This will typically be based on the type of questions being asked, the need for follow up questions, and the budget available.
 - b. If probing is required, a listening event is preferred. If a representative sample is required, a survey will likely be better.

3. You could test topics in your initial invites, request feedback and amend your plan before the event / survey.
4. Planning and running a listening event.
 - a. Set a date and time and find a neutral venue.
 - b. Invite potential attendees through known organisations. You could choose to ask for expressions of interest in order to select a specific group. If doing this, you will need to register attendees once they have indicated their interest.
 - c. Select a facilitator and identify colleagues and stakeholders to be table facilitators.
 - d. Create a structure and plan for the event - ensure facilitators are briefed on the plan.
 - e. Communicate proposed topics to attendees before event to set expectations and allow preparation.
 - f. Run event.
5. Running a survey
 - a. Select your partner(s) and platforms based on specific audience and resource.
 - b. Draft survey questions based on desired insights – keep as short and neutral as possible.
 - c. Be clear about how responses will be used and only collect personal data if required.
 - d. Set period of time survey will be open for – think about how many responses you want.
 - e. Work with partner(s) to get survey communications circulated to relevant audience.
6. Collect and analyse feedback and responses.
7. Follow-up, where possible, on how insights have shaped work.

Resources required (including time)

- ❖ Significant staff time - time planning and running listening event or survey process. This will involve project and stakeholder management. Analysis of feedback and insights can be time-consuming.
- ❖ Costs - for a listening event these will include facilitator, venue and refreshments; for a survey there may be a software cost, consultancy fee or market research cost.

Significant risks and mitigation

- Insights gathered through survey or discussion don't meet the need of the work, team or organisation.
 - Write a clear brief and make sure the overall objective is well communicated to facilitators, as well as the questions.
 - Ensure buy in from senior management and all relevant stakeholders.
 - Allow time for follow up analysis as part of the project.
- Attendees / respondents are unclear on how their feedback is used and become disillusioned.
 - Set expectations early and often around how feedback will be used and what people can expect to hear afterwards.
 - Set realistic timelines and milestones.
- Feedback is collected and not used.
 - Allow time to consult with senior stakeholders after the feedback is gathered, so they understand what it means and create a plan to use.
 - Ensure all thinking about the choice of listening event or survey is done upfront before commission.
- Listening event – attendee(s) disrupts listening event and derails discussion.
 - Select a confident facilitator with clear plans to deal with disruption.
 - Make attendees register so that a known disruptor is identified in advance.
 - Have people in the room who are there specifically to deal with this type of disruption.
 - As appropriate, deal with or park disruptions as they arise.

Roles and responsibilities for staff

- Teams - discuss and agree topics / questions where feedback is required from a larger group of patients and the public.
- Senior staff - agree objectives and budgets.
- Individual staff - take responsibility for project and stakeholder management.

Measuring impact

The specific aim in this approach is to generate useable insights that can be applied in staff work. The process could be measured through:

- the number of events / surveys.
- the response rate / number of attendees.
- feedback from attendees / respondents on quality of event / survey.

Examples

Listening Event

In October 2019 the University College London Hospitals NHS Foundation Trust Joint Research Office ran a listening event titled '[Your data, our challenge: how do we ensure we get the best healthcare?](#)'. Around 60 patients and members of the public attended. The event started with a panel discussion about data use for research in the NHS and then opened for questions and comments from attendees as well as questions sent in before the event. The event aimed to kick off PPIE efforts and begin the conversation around the themes that mattered most to patients and the public in thinking about health data use.

Survey


In Autumn 2019, the Migraine Trust ran their first ever survey of the whole migraine community, focused on learning more about the experience and priorities of anyone with an interest in migraine and their charity, personal or professional. The results were used to shape the charity's next [five-year strategy](#), launched in February 2020. The survey used the SurveyMonkey platform and was circulated through all known migraine networks.

ADVICE, PERSPECTIVES AND INSIGHT

Guide 3.1.3 - Interviews and focus groups

What is it?

Formalised face-to-face discussions with patients and the public to provide advice and perspectives on relevant aspects of work and planning. These discussions may take place on a 1:1 basis, or in a group setting. A focus group will typically have between five and eight participants. This approach brings together components from individual involvement and listening events and surveys.

★★★★☆	Medium complexity
££	Medium resources required
	Implemented by individual staff

Related PPIE outcome(s)

1. Improving research.
2. Supporting directorate strategy and planning to take account of what matters to the public.
3. Working to shape policy that improves health and care for communities.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- A clear situation where you would like to know more from patients / public.
- Topics and or questions you want to ask about.
- Clarity around audience / people you want to hear from.
- Resources to manage the interviews or focus group process.

Advantages

- iv. Allows time and space for deeper discussion and clearer insights.
- v. Interviews have a better response rate than surveys.
- vi. Allows for flexibility of questions.

Disadvantages

- i. Can be costly and time-consuming.
- ii. Both interviews and focus groups can be easily biased or led by staff or participants.
- iii. No anonymity for respondents.
- iv. Focus groups require management - disagreements can distract from focus.

Applying in your work

1. Be clear on what insights you are seeking and why – having a hypothesis around expected insight may help to clarify what you want to understand.
2. Write a list of the type(s) of people you would like to hear from – background, experiences, skills, perspectives. Be clear about which groups you would prioritise and how many individuals you would like to involve.
3. Think about how you might recognise the involvement contribution (see FAQs, p.46).
4. Set a date and time for interview or focus group and find a neutral venue.
5. Develop materials (this might just be a paragraph in an email) that explain what insights you are seeking, expectations and how people can indicate their interest in being involved.
6. EITHER: Find appropriate groups and networks to advertise involvement through. Where relevant, include groups that operate outside of the 'health' space.
7. AND/OR: Contact known individuals who fit your profile and might be willing to be involved.
8. Follow up with interested individuals.

9. If running a focus group, select a facilitator.
10. Prepare questions for discussion. Create a structure and plan for interview / focus group.
11. Where appropriate, communicate topics to attendees to set expectations. Ask if they have any questions about activity.
12. Do interview / focus group.
13. Tell attendees about next steps and, where appropriate, ask if they would like to be kept updated on specific work.
14. Follow-up with respondents / attendees about how the collected insights are being used.
15. Ask about their experience of being involved, what worked for them and what did not. This should include ability to provide feedback anonymously.

Resources required (including time)

- ❖ Staff time – planning, coordination and follow-up.
- ❖ Staff time – undertake interviews or focus group.
- ❖ Patient/public partner time – taking part in interviews / focus group.
- ❖ Costs - recognition for involvement.
- ❖ Costs – minimal activity costs (e.g. refreshments and venue).

Significant risks and mitigation

- Insights gathered through interviews or focus group don't meet the need.
 - Write a clear brief and make sure the overall objective is well communicated.
 - Ensure buy in from all relevant stakeholders.
 - Allow time for follow up analysis as part of the project.
- Attendees / respondents are unclear on how their feedback is used and become disillusioned.
 - Set expectations around how feedback will be used and what people can expect to hear afterwards.
- Focus group - attendee disrupts and derails discussion.
 - Select a confident facilitator with clear plans to deal with disruption.
 - Speak to potential attendees in advance of the focus group running.

Roles and responsibilities for staff

- ☐ Teams - discuss and agree topics / questions where feedback is required from a larger group of patients and the public.
- ☐ Individual staff - take responsibility for project and stakeholder management.

Measuring impact

As with listening events and surveys, the specific aim in this approach is to generate useable insights that can be applied in staff work. The process could be measured through:

- the number of interviews / focus groups attendees.
- feedback from respondents / attendees and staff on quality of process.

Further resources

[A Bite-Size Guide to Running Focus Groups for Patient and Public Engagement](#), NHS England (2016).


[Using interviews to gather patient insight](#), Cancer Research UK (2019).

ADVICE, PERSPECTIVES AND INSIGHT

Guide 3.1.4 - Patient & Public / Citizen Advisory Group / Board

What is it?

A standing group of patients and the public to be regularly engaged and involved in discussions around the planning and work of the directorate. Members could also be involved in delivery of activities and groups can play a role in transparency.

★★★★★	High complexity
£££	High resources required
	Implemented at directorate-level

Note: Patient Advisory Group members may also be used in any of the other approaches.

Related PPIE outcome(s)

2. Supporting directorate strategy and planning to take account of what matters to the public.
3. Working to shape policy that improves health and care for communities.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- Organisational approval.
- Clarity and agreement around the initial role of the group in terms of advisory, delivery and transparency functions. This should be developed with members over time.
- Agreement on who will be the member of staff responsible for the group.
- Agreed review period (recommend 12 months initially).

Advantages

- i. Regular opportunities to discuss work.
- ii. Ready to involve easily and quickly.
- iii. Signed up to principles, ways of working and confidentiality.
- iv. Better relationships built over time.
- v. Greater potential for representation.

Disadvantages

- i. Setup can be labour-intensive.
- ii. Ongoing costs can be high.
- iii. Power dynamics in a group can enhance already 'loud' voices.
- iv. Patient / public partners on a group may be more likely to become embedded and lose distinct perspective.

Applying in your work

There are four key stages to developing and using an advisory group in your work.

1. Make the decision to set up a patient / public advisory group. There are many suitable structures for groups, depending on the needs of the directorate.
 - a. Work with staff and patients to develop clarity around:
 - i. Role and functions – advisory, delivery, and/or transparency.
 - ii. Activities – what you might ask partners to help with.
 - iii. Terminology – title of the group.
 - iv. Who you want to be part of the group – general background and representation.
 - v. How many people you want on the group.
 - vi. Approach to selection – formal or informal, competitive or not.
 - vii. Arrangements for Chair or Co-Chairs – staff or patient / public partners.
 - viii. Term of initial membership.
 - ix. How regularly the group might meet.

- x. Where / how the group will meet – face to face, virtual or mix.
 - xi. Payment (recognition for involvement) and expenses – what are you able to offer?
 - xii. Staffing to support the setup, running and review of the group.
 - xiii. How disagreements, complaints and concerns will be dealt with.
 - b. Seek directorate, and in most cases organisational, agreement for approach.
 - i. Alternative is to have patients and the public join any existing groups.
 - c. Where agreement for a separate advisory group has been given, engage communications team and begin next steps.
- 2. Develop the communication about the group and undertake selection process. This will vary depending on the selection complexity and role agreed.
 - a. Materials – this could range from a short paragraph about the group to a full person specification and role profile. More detail provides clarity and sets expectations better.
 - i. Ensure materials meet Disability Discrimination Act access requirements – availability in a variety of formats and languages when requested.
 - b. Communication – work with networks and organisations, particularly those that align with the people you are seeking, to get materials in front of people who might be interested in joining the group.
 - c. Undertake selection. As part of this, you will need to think about:
 - i. Deadline for expressions of interest.
 - ii. What you would like to know about those who are interested.
 - iii. Assessment – what criteria you will select on and how you will assess for this.
 - iv. Approach to selection from expressions of interest – how many stages?
 - v. Data governance and management for selection process.
 - vi. Clear communication with those interested throughout.
 - vii. What will happen to those interested who do not get selected?
- 3. Set up the first meeting(s) of the group and run through to the review point. This will vary depending on the complexity of the group role and ways of working.
 - a. Members may be asked to sign relevant documentation around their roles.
 - b. Agree terms of reference, including roles, responsibilities and ways of working.
 - c. Agree method for review / evaluation of group.
 - d. Work with group to support PPIE efforts in the directorate.
- 4. Undertake review of group's function in the work of the directorate, with focus on members' and staff experiences. This might lead to:
 - a. Changes to the role and activities of the group and members.
 - b. Changes to the make-up of the group, potentially further recruitment.
 - c. Changes to the governance of the group.
 - d. Group members choosing to step down at the end of first term.
 - e. Closing down of the group.
 - f. Consolidation with other PPIE activities.

Resources required (including time)

- ❖ EITHER significant staff time OR a consultant – preparation, development and selection.
- ❖ Staff time – ongoing management of group, dependent on complexity.
- ❖ Patient/public partner time – group meetings and involvement activity.
- ❖ Costs – recognition for involvement payment and expenses.
- ❖ Costs – refreshments, other costs dependent on involvement activity.

Significant risks and mitigation

- Finding representative people with distinct perspectives who are able and willing to act as a critical friend can be challenging.
 - Be clear about the variety of skills, experiences and backgrounds you are seeking.
 - Work through different voluntary and community sector organisations (beyond health) that target specific skills, experiences and backgrounds.
 - Develop a selection process that tests for the skills you are looking for.
 - Use other PPIE approaches to bring in less confident voices and experiences.
- Frustration from group members around role of group.
 - Expectations around role and responsibilities agreed with group members early on.
 - Early review of role of group to allow function to evolve in discussion.
 - Regular opportunities for group members to speak with staff about any concerns.
- Group focus on PPIE process, not outcomes.
 - Work with members to set agenda that emphasise outcomes through activity.
 - Select individuals who are keen to 'do' as well as reflect on PPIE efforts.
 - Ensure clarity around the review process.
 - Select a strong, decisive, outcomes-focused Chair or Co-Chairs.

Roles and responsibilities for staff

- ☐ Senior staff – agreement and sign off.
- ☐ Communications team – ensure awareness of plan.
- ☐ Nominated 'advisory group support' staff member(s) – develop, select, run and review advisory group. Be available for contact from members. Support others in engaging with advisory group.
- ☐ Individual staff – responsibility for opportunities to consult or involve members.

Measuring impact

Review against anticipated outcomes, functions, ways of working and insights gathered through advice and discussion. Emphasis should be on the things that have been included, reviewed or changed because of advice from the group, as a whole or from individual members. Ease of use for staff, and staff time and costs, will be worth including in review. This could be done through formal evaluation, interviews, surveys or a mixed methods approach. It is recommended that Patient Advisory Group members are initially appointed for a short term with early review and adaptation planned.

Example

Health Data Research UK established a [Public Advisory Board](#) in January 2019, at the start of their PPIE efforts. The group is responsible for:

- Providing strategic advice to Health Data Research UK's Senior Management and Board
- Embedding patient, carer and public involvement and engagement
- Supporting efforts to earn public trust and confidence in health data research
- Supporting accountability

Members were selected from around a hundred applications through a rigorous and competitive application process, allowing room for the Advisory Board to grow in the future. Members come from a variety of backgrounds and perspectives, including patients, carers and the public and professionals working in engagement and involvement activities. The Public Advisory Board meets every two months and its members provide input on projects in between meetings. Members' initial tenure was for 12 months and all were extended for a second year.

3. How do we involve and engage?

3.2 Assessment, selection or review

This is a group of approaches that aim to support assessment, selection and decision-making processes by asking questions about PPIE activity, assessing against PPIE criteria, and involving patients and the public in the assessment / selection / decision-making process.

The other groups of approaches are:

- 3.1 Advice, perspectives and insight.
- 3.3 Developing or reviewing written materials.
- 3.4 Presenting or training.
- 3.5 Actively involving in delivery of work.

What will these approaches help us achieve?

Funding decisions and wider assessment and selection that take involvement and engagement into account and work to ensure that what matters to patients and the public is factored into decision-making. This may also be used as part of recruitment processes and staff development reviews.

Approaches

The following guides outline three approaches:

- 3.2.1 Asking questions about efforts to engage and involve patients and the public.
- 3.2.2 Assessing against criteria.
- 3.2.3 Patient / public assessors.

While these have been separated into distinct approaches, this is a group where blending approaches may be appropriate at different stages of a process.

It is never too late to ask questions about efforts to engage and involve patients and the public.

Measuring impact of these approaches

Potential aims:

1. Fund projects where patients and the public are actively involved or have plans to do so.
2. Fund projects that have considered patient and the public perspectives or have plans to do so.
3. Ensure patient and public perspectives and values are reflected in funding decisions.
4. Embed PPIE in staff recruitment and review processes; to
5. Ensure staff have awareness of the importance of PPIE and are working to undertake PPIE in their work.


The first step in funding projects where patients and the public are actively involved (1) is to ask questions about PPIE in the application process. This is the first outlined approach. Measuring impact in these approaches is a mix of applying them and assessing process and confidence.

ASSESSMENT, SELECTION OR REVIEW

Guide 3.2.1 - Asking questions about efforts to engage and involve patients and the public

What is it?

This is simply about asking applicants or staff if they have considered PPIE in a specific context. It is the first stage in making decisions that consider PPIE activity. This might be in applications for funding, job interviews, with external consultants or in annual staff reviews. This stage involves nothing more than asking questions, which act as a prompt and encouragement for activity.

★★★★★	Low complexity
£	Low resources required
	Implemented by teams

Related PPIE outcome(s)

2. Supporting directorate strategy and planning to take account of what matters to the public.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- Willingness to ask.
- Plan for what you will do with answers.

Advantages

- i. Simple.
- ii. Easy to enact.
- iii. Able to apply on a one-off basis.
- iv. Indicates importance of PPIE in work of the directorate.

Disadvantages

- i. Asking without plans to specifically assess might be seen as tokenistic or not worth doing.
- ii. Adds another topic for applicants and/or staff to answer – increasing length of responses.

Applying in your work

Questions will need to flex to the specifics of the activity but could be based around:

- Past or current activities – what have you done [are you doing] to involve or engage patients, carers and the public in your work?
- Future activities – how do [might] you plan to involve or engage patients, carers and the public in this work?
- Influence – how has engaging with patients, carers and the public influenced your work / plans / approach?
- Value – is there value in involving or engaging patients, carers and the public in your work?
- Outcomes – why is this work important in terms of improving the health of patients, carers and the public?
- Outcomes – what would you like to achieve through involving and engaging patients, carers or the public in this work?
- Potential – how might patients, carers and the public contribute to your work?
- Thinking – have you thought about involving or engaging patients, carers and public in your work? If so, what are your thoughts?

It would be worth discussing what the right question is, in the specific context, with current award-holders and staff. The question(s) may evolve over time. Detail on specific activities (interviews; working with established groups; using data from third sector organisations) is worth encouraging.

Resources required (including time)

- ❖ Minimal staff time – add question to application / interview / discussion points.
- ❖ Staff time – review answers and reflect on how answers might be used.

Significant risks and mitigation

- Small risk around asking a question that is not formally assessed and applicants / staff understanding of the role of the question.
 - Clarity around what you hope to get out of, or achieve through, asking the question.
 - Clear communication about why you are asking the question(s).

Roles and responsibilities for staff

- ☐ Senior staff – discuss inclusion of appropriate question in staff annual reviews.
- ☐ Teams – where relevant, agree where and when to ask question.

Measuring impact

Specific emphasis in this stage on growing awareness of PPIE efforts and confidence in asking about others' PPIE work within the directorate.

Example

The directorate's Advancing Applied Analytics programme asked the following question as part of round four written applications:

"Please describe how you will involve patients and the public in each stage of your project. Please also outline the different stakeholder groups that you have included in this application. (Clinicians, senior managers, patients/users, carers and general population) 1375 character limit (approximately 250 words)."


This has demonstrated the value of PPIE to applicants and is providing early insight for the team on how analytics projects around the country are working to involve and engage patients and the public in their work.

ASSESSMENT, SELECTION OR REVIEW

Guide 3.2.2 - Assessing against PPIE criteria

What is it?

This involves asking questions, which are then assessed against defined PPIE criteria as part of a formal assessment / selection process. As with the previous approach, this might be in applications for funding, job interviews, with external consultants or in annual staff reviews. This builds on the previous approach by formally assessing the response.

★★★★★	Medium complexity
£	Low resources required
	Implemented by teams

Related PPIE outcome(s)

2. Supporting directorate strategy and planning to take account of what matters to the public.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- Willingness to ask questions about PPIE efforts.
- Criteria for assessing against.
- Confidence in being able to assess answers.

Advantages

- i. Relatively easy to enact.
- ii. Able to apply on a one-off basis.
- iii. Indicates importance of PPIE in work of the directorate.
- iv. Assessment on this basis creates incentives for PPIE activity.

Disadvantages

- i. Adds another topic to assessment / selection / review processes.
- ii. Confidence in assessing against PPIE criteria will be variable.

Applying in your work

Potential questions are listed in guide 3.2.1. Criteria for assessment will depend on the question(s) asked but could include:

- Evidence of contribution PPIE could make.
- Evidence of awareness of value of PPIE.
- Experience in undertaking PPIE.
- Understanding of work in wider health and care improvement context.

Resources required (including time)

- ❖ Staff time – add question to application / interview / discussion points.
- ❖ Staff and assessors time – to assess against criteria.
- ❖ (Potential) minimal staff time – training to assess against criteria and build confidence.

Significant risks and mitigation

- PPIE might not be perceived as relevant to health data science work and awards.
 - Asking the question implies that it is relevant and important.
 - Clear communication about why it is relevant and important.
- Lack of clarity around how assessment is undertaken leads to reputational risks.
 - Clear communication about criteria for PPIE assessment will work.

Roles and responsibilities for staff

- Teams – where relevant, agree where and when to ask question and which criteria will be used to assess; provide guidance to assessors; if agreed, attending training on how to assess.

Measuring impact

Emphasis in this stage on the impact of including PPIE in wider assessment criteria, selection and decision-making, and how it shapes the selections and decisions made.

Example

The [Mid and South Essex STP Innovation Fellowship](#) asks applicants about how potential users have been involved in the development (and testing, where appropriate) of the innovation (note: this might include clinicians and other professional staff). Applications are then assessed against the strength of all answers and assessors provide detailed comment. Applications are selected for interview on the basis of this assessment.


In the interviews, shortlisted applicants are again asked to talk about patient and practitioner involvement. Selected innovations invariably have strong user involvement in their development and Innovation Fellows are aware of the importance, to the STP, of ongoing involvement and engagement work. This is backed up with continued support and learning opportunities for fellows around involving patients and the public in their work.

ASSESSMENT, SELECTION OR REVIEW

Guide 3.2.3 - Patient / Public Assessors

What is it?

This approach involves including patients and the public as assessors or members of a selection panel. In this role they should function like any other member of the assessment, selection or review team with the same rights, responsibilities, and role. Patients and the public will bring unique perspectives, skills, and experiences to the process.

★★★★☆	Medium complexity
££	Medium resources required
	Implemented by teams

Related PPIE outcome(s)

2. Supporting directorate strategy and planning to take account of what matters to the public.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- Assessment, selection or review process.
- Agreement from senior staff to involve patient / public assessors.
- Clarity on what stages of the process you would like patient / public assessors involved in.

Advantages

- i. Relatively simple to enact.
- ii. Reduction in power inequalities in feedback where assessed independently.
- iii. May be involved in wider decisions about criteria, strengthening perspectives in assessment process.

Disadvantages

- i. May require more briefing and debriefing.
- ii. In group settings power inequalities may be heightened.
- iii. Representation of population not possible but importance here is on increasing varied perspectives feeding into process.

Applying in your work

1. Where possible, plan for patient / public assessors involvement as far in advance as possible.
2. Decide how many patient / public assessors you would like to involve in your process and, where you have more than a week, what background, skills and experiences they would ideally have.
3. Develop a short brief and include what recognition for involvement/expenses is available.
 - a. If you have three weeks or more until assessment/selection takes place, circulate brief through contacts, networks and relevant organisations asking for interested individuals to get in touch.
 - b. If you have more than a week but less than three weeks, create a longlist from those you have involved in the past and contact relevant individuals about taking part.
 - c. If you have a week or less, contact one or two known contacts about taking part.
4. Either brief individually as patient/public assessors come on board or as a group. Recommend both a written and verbal briefing to reflect differences in how people learn.
5. Some individuals may want a more hands-on training session, particularly if they haven't sat on selection/assessment panels before. Where time and resource are available, this may be delivered in house by team members or by an external trainer.
6. Ensure individuals have had a chance to ask any and all questions they might have about the process and their role in it. Be clear about how their feedback will be used.
7. Provide clear opportunities for patient / public assessors to declare any conflicts of interest.
8. Remind assessors of the timeframes. Where they are being involved in an in-person selection panel, ask if they would like a pre-panel chat to answer any final questions.

9. Run assessment, selection, or review process.
10. Follow up with thanks and recognition for involvement / payment of expenses form. Include detail on how their feedback has been/is being used.

Resources required (including time)

- ❖ Staff time - plan patient / public assessor involvement, develop communication and circulate.
- ❖ Staff time - brief and de-brief patient / public assessors.
- ❖ Costs - recognition for involvement and/or payment of expenses.

Significant risks and mitigation

- Finding people to involve in individual activities can take some time, especially early-on in PPIE work where an established contact list does not exist.
 - Work through individuals, organisations, groups and networks with established contacts.
 - Keep communication simple and clear.
 - Create a GDPR-compliant list of individuals who are interested in being involved.
- Patient / public assessors pursue own agenda.
 - Develop clear selection criteria around ability to focus on wider interests and needs.
 - Talk with potential assessors about bias and areas of interest.
 - Include a conflicts of interest declaration as below.
- Conflicts of interest not declared by patient / public assessors.
 - Brief includes sentence about how conflicts of interest will be dealt with.
 - Include a conflicts of interest declaration.
 - Provide further written and verbal opportunities for conflicts of interest to be raised.

Roles and responsibilities for staff

- ☐ Teams - agree where patient / public assessors might be involved in a process, where appropriate seek approval from senior staff.
- ☐ Senior staff - where appropriate, approve involvement in process.
- ☐ Individual staff - take responsibility for all or parts of the planning, preparation and delivery of process.

Measuring impact

The impact here is the reflected in how much decisions made have been influenced or changed by the perspectives of patient / public assessors. The aim is to make decisions and selections that reflect the things that matter to practitioners, patients and the public in this area.

Assessment of this is likely to be more qualitative than quantitative, however there are process metrics that can be measured including:

- Number of patient / public assessors involved.
- Process involvement rating by patient / public assessors.
- Percentage of selections supported and not supported by patient / public assessors.
- Feedback from patient / public assessors and staff about experience and insight.

Example

The NHS Innovation Accelerator asks questions about patient and public involvement in the development of applicants' innovations and uses patient / public assessors as part of the wider assessment and interview processes. Every application is reviewed by a patient / public assessor and all interview panels include a patient or member of the public.

NHS Foundation Trust Governors take part in [non-executive director and chair recruitment](#).

3. How do we involve and engage?

3.3 Developing or reviewing written materials

This is a group of approaches focused on engaging wider audiences in your work and involving patients and the public in written communication of work. This includes blogs and social media but not podcasts or video material (covered in 3.4).

The other groups of approaches are:

- 3.1 Advice, perspectives and insight.
- 3.2 Assessment, selection or review.
- 3.4 Presenting or training.
- 3.5 Actively involving in delivery of work.

What will these approaches help us achieve?

These approaches focus on written communication that clarifies, simplifies and engages. This should lead to written communication about work that engages a wider, more diverse audience.

Approaches

The following guides outline two approaches:

- 3.3.1 Patient Data Citation.
- 3.3.2 Writing for public audiences – including patient / public partners as co-authors and reviewers.

If you are looking for approaches that deal with verbal communication, please see 3.4 (pp.34-40).

Measuring impact of these approaches

Potential aims:

- 1. Increased awareness of where patient data is used.
- 2. Increased transparency around how health data is accessed and used; leading to
- 3. Increased public trust in how health data is used in research.

While the first aim is specifically relevant to research done in the Data Analytics directorate, the aims around transparency (2) and public trust (3) are in many respects health data research sector-wide aims and should be treated as such.

Evidence of being transparent and building public trust will need to focus on activities that publicly, and clearly, communicate how health data is accessed and used in research. Assessment may be through working with other health data research organisations and relevant partners.


DEVELOPING OR REVIEWING WRITTEN MATERIALS

Guide 3.3.1 - Patient Data Citation

What is it?

A sentence used as a [data citation](#) to reflect sources of health data. It is to be included when publishing research that uses patient data. It was developed by patients & carers in the [use MY data](#) movement:

"This work uses data provided by patients and collected by the NHS as part of their care and support"

★★★★★	Low complexity
£	Low resources required
	Decision made at Directorate level

Related PPIE outcome(s)

1. Improving research.
3. Working to shape policy that improves health and care for communities.

What needs to be in place?

- Completed analysis with plans to communicate results.

Advantages

- i. Recognises patient data as a valuable asset.
- ii. Raises awareness of how patient data is accessed and used.
- iii. Aligns Health Foundation with other organisations using patient data for research, as well as use MY data and Understanding Patient Data.

Disadvantages

- i. Not proactive engagement or involvement.
- ii. Does not address diversity or inclusion.

Applying in your work

This citation may be used on all work, written and spoken, underpinned by patient data including blogs, publications, presentations, event materials & press releases.

1. Discuss use with [use MY data](#) and [Understanding Patient Data](#).
2. Explore whether appropriate for inclusion in requests to award holders.
3. Develop a comprehensive list of communication materials used by the team.
4. Agree approach with senior staff.
5. Find one-step simple method to embed citation in specific materials. This might include adding it to slides and reporting templates.
6. Speak with Health Foundation Communications team about inclusion in relevant blog posts and press releases.
7. Raise awareness in the team about use of the data citation.
8. Find one of the team to be the 'data citation' champion, checking for inclusion.

Resources required

- ❖ Staff time - to discuss use, develop list and find simple methods to embed.
- ❖ Senior staff time – to agree use.
- ❖ Space on communication materials for extra sentence.
- ❖ Potential member of staff as 'data citation' champion.

Significant risks and mitigation

- May increase questions to the team about sharing of patient data and access.
 - Questions bring the opportunity to raise awareness and encourage public discussion – not necessarily a bad thing.
 - Potential for named member of staff to answer questions about this.
- May increase concerns raised with the team about access to specific sets of data.
 - As above.

Roles and responsibilities for staff

It is likely the support of senior staff in the Directorate will likely be needed.

- ☐ Senior staff – discuss and agree which communication materials will include citation and discuss methods to embed.
- ☐ Communications team – agreement and discussion of method to embed in comms-published content.
- ☐ Individual staff – responsibility to include in their work underpinned by patient data.
- ☐ Award holders – where applicable, encouraged to include in their communication.
- ☐ Potential ‘data citation’ champion – responsibility to champion in directorate, check published materials for citation and answer questions about citation from staff and the public.

Measuring impact

Aim: Increased awareness of how patient data is used.

It will be difficult to assess the causal impact of the team’s use of the data citation in contributing to awareness of how patient data is used. However, a small number of process measures could support evaluation of this, including:

- Number of blog / press release / article views where citation is used.
- Number of people seen presentation including citation.
- Other organisations using Patient Data Citation.

These would indicate growing awareness of the Patient Data Citation, with the potential correlation to growth in awareness of how patient data is used. A wider assessment of awareness of how patient data is used could also be commissioned.

Example

The citation has been adopted national bodies such as the NIHR, Public Health England, the Office for National Statistics and many research charities.


In July 2019, Health Data Research UK [published their Attribution Policy](#), including emphasis on the Patient Data Citation. Researchers and technologists who are supported by Health Data Research UK are asked to follow the policy, including to “use the patient data citation to properly acknowledge the role of patients and the public.”

DEVELOPING OR REVIEWING WRITTEN MATERIALS

Guide 3.3.2 - Writing for public audiences – including patient / public partners as co-authors and reviewers

What is it?

This is a two-purpose approach - first there is writing more about your work for public audiences (engagement) and second there is working with patients and the public to develop written content that is specifically for public audiences. The outputs will broadly be the same, but the process will look different. This approach includes lay summaries.

★★★★☆	Medium complexity
££	Medium resources required
	Implemented by teams

Related PPIE outcome(s)

1. Improving research.
3. Working to shape policy that improves health and care for communities.

What needs to be in place?

- A topic, or work, to write about.

Advantages

- i. Relatively simple.
- ii. Low cost.
- iii. Involvement improves content.

Disadvantages

- i. Simplifying language takes time and practice.
- ii. Representation not possible.
- iii. Significant impact uncertain.

Applying in your work

1. Decide whether you are simply writing for public audiences or involving patients and public in writing for public audiences.
 - a. Decisions around this are likely to relate to time, resource, involvement in wider work, and perceived importance of topic to/for public audiences.
2. If writing content for public audiences:
 - a. Write and then work to simplify language.
 - b. Ask colleague to review for jargon or complex terms that might need simplification.
 - c. You could choose to involve patients or the public in reviewing the piece at this stage.
 - d. Reflect on reader assumptions that might underpin your piece.
 - e. Remember that simplification should not mean it loses meaning, and metaphors can help to explain complex theories.
3. If wanting to involve people in writing for public audiences:
 - a. Decide whether you want to involve in the topic or work (potentially understanding what matters related to it), in the review of content, or the writing of content.
 - b. Where involving in the topic or work you will need time. See the Advisory approaches (3.1, pp.11-21) for ways to enact this. Ideally, work with them to storyboard the piece from the outset.
 - c. Where involving in reviewing content, you will write and develop the content drafts and share with people (1-3) for review. Details for where to find people are in the FAQs.
 - d. Where involving in writing the content, decide whether you will co-write or ask someone to write and you review.
4. Patient and public partners could work with you to decide which topics and approach to these are most useful for public audiences.

Resources required

- ❖ Staff time – planning approach and writing / reviewing content (will depend on approach).
- ❖ Costs - recognition for involvement and payment of expenses.

Significant risks and mitigation

- May be seen as tokenistic if approached from solely an engagement or review basis.
 - Do as part of wider involvement and engagement work.
- Those involved not perceived as 'representative enough' of UK population.
 - In this specific approach, diverse perspectives are valuable but pragmatic working on the basis that any input is better than no input is sensible.
 - Ensure diversity of perspective across wider involvement and engagement work.
 - Work out who the likely audience are and involve them.
- May be overly complex language or filled with technical jargon.
 - Think about health literacy in the audience for the piece.
 - Get colleagues to review and simplify content.
 - Be aware the average reading age in the UK is 9.

Roles and responsibilities for staff

- ☐ Teams - decide on areas, or pieces, of work that might benefit from this and agree approach.
- ☐ Individual staff - take forward as appropriate.

Measuring impact

Impact in this specific approach relates to the broader aims of:

1. Increased awareness of where patient data is used.
2. Increased transparency around how health data is accessed and used; leading to
3. Increased public trust in how health data is used in research.

Related process measures might include:

- Number involved in writing for public audiences, at what stages of the process.
- Changes to content from patient / public partners involved in process.
- Staff feedback on involvement.
- Where online, page views for co-produced content.

Further resources

Many organisations promote and support the creation of summaries of research that explain complex ideas and technical and scientific terms to people who do not have prior knowledge about the subject.

[Writing a good lay summary](#). Diabetes UK (2020)

[Guidance for anyone who is planning to write about biomedical or health research for a non-specialist audience](#). Access2Understanding (2020).

3. How do we involve and engage?

3.4 Presenting or training

This group of approaches are focused on opportunities for engagement and involvement in verbal communication around the work of the directorate. These approaches focus on engaging a wider audience in the work of the directorate, and involving patient and public partners in presenting to, and training, staff.

The other groups of approaches are:

- 3.1 Advice, perspectives and insight.
- 3.2 Assessment, selection or review.
- 3.3 Developing or reviewing written materials.
- 3.5 Actively involving in delivery of work.

What will these approaches help us achieve?

These approaches aim to build partnerships and understanding between staff and patients and the public. All are 'higher-profile' involvement or engagement that can support efforts to demonstrate the value of PPIE to the directorate and encourage ongoing activity.

Approaches

The following guides outline two approaches:

- 3.4.1 Speaking to public audiences.
- 3.4.2 Patient / public speakers at directorate events.
- 3.4.3 Training.

Measuring impact of these approaches

Evaluating this group of approaches requires exploring the impact across three high-level aims:

- Increased public trust in how health data is used in research.
- Increased application of patient / public perspectives in work of the directorate.
- Increased variety of perspectives in learning and training opportunities that leads to clear value for staff.


These form part of evaluating PPIE across the work of the directorate. There are also more short-term aims and metrics that may help to evaluate the processes. These are detailed in each guide and should build towards the high-level aims listed above.

PRESENTING OR TRAINING

Guide 3.4.1 - Speaking to public audiences

What is it?

This is a way of getting your messages and work in front of new audiences. Patients and the public are interested in health data use in the conclusions that are reached from data science. This approach allows and encourages patients and the public to hear about and engage with your work. This could be through podcasts, video and other digital media.

★★★★★	Low complexity
£	Low resources required
	Implemented by individual staff

Related PPIE outcome(s)

1. Improving research.
2. Supporting directorate strategy and planning to take account of what matters to the public.
3. Working to shape policy that improves health and care for communities.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- Events for public audiences on relevant topics.
- Staff willing and able to speak about their work.
- Confidence in speaking to public audiences about work.

Advantages

- i. Relatively simple to enact.
- ii. Potential to engage with new audiences who may not know the Health Foundation.
- iii. Builds relationships with other relevant organisations running public events.

Disadvantages

- i. Adds complexity to communication around work.
- ii. Requires confidence from staff in communication and presentation.

Applying in your work

This approach will require proactive and reactive work. The proactive side requires engaging and building relationships with organisations who run public events. The reactive work is to identify and take up opportunities to speak at already-planned public events.

You could choose to speak at an event where there is a mix of patients, public, and professionals, or even where there are only a few patients and public attending.

1. Identify organisations that run appropriate and relevant events for public audiences where you could speak.
2. Identify appropriate and relevant events for public audiences where you could speak.
3. Talk to organisations about taking opportunities to speak at public events.
4. Once you have agreed to speak at a public event develop content.
5. Think about what content will be most suitable for the event audience. Ensure that any professional terminology and acronyms are clearly explained.
6. Think about what questions patients and the public might have about your work and try to answer some of these during your presentation.
7. Do not underestimate the background and experience of the public and patients. There may be people in the room who know, and understand, a significant amount about the topic you are speaking or the process you have gone through.

8. Be confident but do say If you don't know the answer to a question. There is nothing wrong with saying "let me get back to you on that".
9. Think about putting presentations, or a version thereof, on the website or somewhere appropriate where ongoing engagement can be monitored.

Resources required (including time)

- ❖ Staff time – to identify events and organisations with opportunity to speak with public audiences.
- ❖ Staff time – to prepare content and presentation for public audiences.

Significant risks and mitigation

- Background and expectation of public audience are not well understood and content does not match this.
 - Ensure you have clarity around the background and expectation of the audience. What are the insights they are expecting to hear from you?
 - Start and end your presentation with a clear overview of what you are going to talk about/what you have spoken about.
- Significant staff time is spent on identifying and preparing for opportunities to speak to public audiences.
 - Ideally staff will be invited to speak about relevant and appropriate topics at public events by the organisations running them. This may, however, take some time to develop. To mitigate this risk, staff should be thinking about communicating with public audiences early on in their projects and work.
 - Preparing content for public audiences will take time. Staff will, however, get quicker at preparing presentations for public audiences with more confidence and practice. The more it is done, the easier and quicker it will get.
- Insights are simplified to such a degree that work is misunderstood by public audience and misconstrued on other communication channels.
 - Be clear about what you were trying to say and why.
 - Start and end presentations with clear overview of the insights you are sharing.
 - While simplification of insights may be necessary the essential focus is to simplify the language not the content.

Roles and responsibilities for staff

- ☐ Teams – discuss opportunities for communication of work with public audiences regularly.
- ☐ Individual staff – identify and engage around opportunities for speaking with public audiences. Seek out organisations that might provide these opportunities.

Measuring impact

Aim: to raise awareness of directorate work with patient and public audiences.

Impact of this approach will be assessed largely through the evaluation forms of other organisations. However, it sits within wider work to raise public awareness and should be assessed as such by the directorate. Impact could be assessed by some of the following:


- Speaker rating.
- Understanding of content.
- Simplicity of language.
- Perceived confidence of speaker.
- Interesting approach to content delivery.
- Website hits following presentation.
- Follow-up at and after event by audience members.

PRESENTING OR TRAINING

Guide 3.4.2 - Patient / public speakers at events

What is it?

Having patient speakers at directorate events provides an opportunity to bring in perspective on relevant topics and or their experiences. Patients or members of the public could be panelists, facilitators, keynote speakers. A dedicated [patient panel](#) could provide insights throughout.

★★★★★	Low complexity
£	Low resources required
	Implemented at Directorate level

Related PPIE outcome(s)

2. Supporting directorate strategy and planning to take account of what matters to the public.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- An event to invite patient / public speaker to.
- Clarity on what you would like speaker to speak about.

Advantages

- i. Brings different perspectives into the room.
- ii. Encourages empathy.
- iii. Cheap and simple.
- iv. Allows for ongoing dialogue.

Disadvantages

- i. May be seen as tokenistic.
- ii. Finding person to set right tone can be difficult.
- iii. Need briefing.
- iv. Needs to clearly align with wider event agenda.

Applying in your work

1. Identify event where patient / public speaker would provide useful and/or interesting perspectives.
2. Identify insight you would like speaker to cover.
3. Decide what you are able to provide in terms of recognition for involvement and payment of expenses.
4. Talk to voluntary and community centre organisations about appropriate person.
5. Speak with interested people to assess story and tone.
6. Pick or choose your speaker based on clear brief.
7. Provide full briefing.
8. Have event with speaker.
9. Follow up with debrief.

Resources required (including time)

- ❖ Staff time - to prep brief and debrief
- ❖ Costs - recognition for involvement and payment of expenses

Significant risks and mitigation

- Lack of clarity around desired insight leads to uncertainty around expectations on both sides.
 - Clear communication of expected insights at every stage.
- Significant staff time spent trying to find a person to involve.

- Working through voluntary and community sector organisations and other patient / public groups.
- Selected speaker speaks off topic at event (and/or afterwards) and loses audience and risks reputation.
 - Clear communication of expected insights at every stage.
 - Select the right person, not the first person.
 - Accept this may happen. Be prepared to say a few words afterwards to link what they have said with the wider agenda.
 - Speak to speaker about how they could usefully support positive messaging around the event (if willing).

Roles and responsibilities for staff

- ☐ Teams – agree events which patient public speakers are appropriate.
- ☐ Individual staff – when planning events, think about why a patient or public speaker should not be included.
- ☐ Communications team – aware of upcoming events with patient and public speakers.

Measuring impact

While encouraging staff and attendees to view issues from a perspective, the aim here should be to change thinking or practice based on speaker's insights. Ideally you want to measure this longer term. Those running the event should debrief on how speaker has changed the shape and tone of the event and feedback where appropriate.

Example

In November 2018, Compassion in Dying launched a policy document setting out their vision, and the culture and practice changes needed to truly deliver person-centred care with respect to life-changing illness.

As part of the launch event, they invited a patient speaker who had been involved in interviews for the report to provide their perspectives on person-centred care for people living with life-changing illness. The speaker was part of a panel who each spoke for 5-10 minutes and then responded to questions.


The patient speaker changed the shape of the conversation and tone by refocusing what content of the report meant for people's lives day-to-day and encouraged a largely professional audience to reflect on the application in their roles. Lots of the audience found the patient speaker's reflections the highlight of the event.

PRESENTING OR TRAINING

Guide 3.4.3 - Training

What is it?

Involving patients and the public in developing and delivering training in relevant topics for staff. In the first instance this might be training in involvement and engagement however there is scope to involve patients with relevant backgrounds in the development of other training (i.e. data security and management; data analysis).

★★★★☆	Medium complexity
££	Medium resources required
	Implemented by teams

Related PPIE outcome(s)

1. Improving research.
2. Supporting directorate strategy and planning to take account of what matters to the public.
4. Improving how we involve and engage patients and the public in the longer-term.

What needs to be in place?

- Identified need for training.

Advantages

- i. Has ability to redress power imbalances.
- ii. May bring training to life through personal experience.
- iii. Development opportunity for less experienced partners to observe and learn from patient leaders.

Disadvantages

- i. Requires specific skills, which often can be learned but this takes time.
- ii. Skill requirements limit representation.

Applying in your work

It is important to note that this approach focuses on patient / public trainers bringing their explicit patient, carer or public perspectives to training. There are patient / public trainers who have significant experience in delivering training and bring their unique perspectives. The latter should be treated as professionals and remunerated at professional market rates. In this, the process is treated more like assessment or selection with criteria around patient / public perspectives.

1. Develop brief for work, including scope for involvement of patients in developing and/or delivering the training. Briefly outline skills required, expectations and payment and expenses.
2. Use networks to identify appropriate patient leader(s) to involve in training development and/or delivery.
3. Speak with interested people about their background, skills and experience to develop and/or lead training for this topic.
4. Consider involving less experienced patient / public partners to observe and learn from patient/public trainer.
5. Work with patient/public trainer to develop learning objectives, set agenda and create activities. Co-develop evaluation materials.
6. If co-delivering training, then decide, between yourselves, how best to split agenda and activities - roles for the session.
7. Think about doing practice sessions, even remotely.
8. Run training.
9. Follow-up and involve patient/public trainer in evaluation.

Resources required (including time)

- ❖ Staff time - to prepare, brief, train and debrief (this will be significant staff time in early efforts).
- ❖ Significant patient / public partner time – to prepare, train and debrief.
- ❖ Costs - recognition for involvement and payment of expenses.

Significant risks and mitigation

- Training / learning is not delivered at appropriate level and staff lack required understanding.
 - Ensure brief is clear, outlining curriculum and expectations for attendees learning.
 - Where working with new patient / public trainer, deliver training together.
 - Co-develop evaluation materials.
- Patient / public trainer does not have the appropriate skills to deliver high quality training.
 - Be clear about desired skills and experience.
 - Undertake a selection process to engage potential trainers.
 - Do not be afraid to interview or discuss their skills and experience.
 - Develop new patient / public trainers through shadowing.
- Significant staff time is spent preparing for co-delivered training.
 - Think clearly about the value you hope and expect the patient / public trainer to bring.
 - Start small – with a new co-trainer delivering less of the total.
 - This improves greatly over time as relationships form – with better understanding of strengths and weaknesses.

Roles and responsibilities for staff

- Teams – think about where patient / public trainers might be appropriate for delivering training, support staff to prepare, brief and train with patient / public trainers.
- Individual staff – prepare, brief, train and debrief with patient / public trainers.

Measuring impact

Training evaluation should be focused on the learning objectives and whether they have been met or not for attendees. There is additional evaluation to be done around the added value of the patient / public trainer and this is probably best done as part of wider monitoring. It is important to get the patient / public trainers' feedback and sense of value.

Example

The Point of Care Foundation deliver a [Foundations of Patient Experience course](#), which includes a day on patient involvement methodologies. This is taught with a small number of patient / public trainers who deliver content, reflect on their own experiences and run activities. Their expertise in involvement provides valuable insights and builds confidence in attendees to work with, and involve, patients and the public in their work.

3. How do we involve and engage?

3.5 Actively involving in delivery of work

This is one approach that moves from involving patients and the public in activities planned by staff, to planning and delivering work with patient / public partners. There is overlap with all the other groups of approaches but the emphasis shifts from reactive to proactive involvement.

As a reminder, the other groups of approaches are:

- 3.1 Advice, perspectives and insight.
- 3.2 Assessment, selection or review.
- 3.3 Developing or reviewing written materials.
- 3.4 Presenting or training.

What will this approach help us achieve?

This approach aims to create strengthened, richer work that has the meaningful involvement of patients embedded in one or more stages of delivering work.

Example activities


- Running involvement or engagement activity – perhaps interviews or focus groups.
- Analysing data.
- Developing insights and conclusions.
- Co-authoring research outputs.
- Writing lay summaries.
- Presenting on substantive work.

ACTIVELY INVOLVING IN DELIVERY OF WORK

Guide 3.5.1 - Patients as co-researchers

What is it?

This refers to a participatory method of research that encourages patients and the public as joint contributors and investigators to the findings of a research project. This uses other approaches but moves from involving patients in the process to involving patients in delivering the research / work process. In its most complex form this becomes research led and co-led by patient contributors. This should feel like partnership working.

★★★★★	High complexity
£££	High resources required
	Decision-making at a directorate level

Related PPIE outcome(s)

1. Improving research.
2. Supporting directorate strategy and planning to take account of what matters to the public.

What needs to be in place?

- [Early] plans for a piece of work.
- Process for undertaking work.
- Resource to support involvement in one element.

Advantages

- i. Doesn't need to be applied to whole research process, could be part of one or more stages.
- ii. Powerful insights from different perspective that may be systematically integrated into analysis.
- iii. Builds relationships between staff and patients.

Disadvantages

- i. Requires trust and respect.
- ii. Potential for confusion over role.
- iii. Significant complexity and cost.
- iv. Training required.
- v. Requires skilled patient partners.
- vi. Representation.

Applying in your work

1. Select part of process you would like to involve a patient or member of the public in delivering with you. This could include:
 - a. In research, design, data selection, analysis, dissemination, evaluation...
 - b. In project, planning, development, delivery, evaluation, publication...
2. Get agreement on how much resource is available to support involvement in delivery.
3. List the activities that make up that part of the process.
4. Think about how these activities could be shared with a skilled patient / public partner. Think about where, or within which topics, patient / public insights would benefit the work.
5. Define the role for the patient / public partner, reflecting on the activities and insights. Depending on which part of the process has been chosen, the time commitment required and the complexity of the task, this may benefit from a role description being drawn up.
6. Be clear about:
 - a. What documentation (e.g. NDA, confidentiality agreement etc) will need to be signed before patient / public partner can get involved.
 - b. What expenses and recognition for involvement payment are offered.
 - c. If they will be a co-author on publications.

7. Develop materials (this might just be a paragraph in an email) that explain what insights you are seeking, expectations and how people can indicate their interest in being involved.
8. EITHER: Find appropriate groups and networks to advertise role through.
9. AND/OR: Contact known individuals who fit your profile and might be able and willing to be involved.
10. Follow up with interested individuals either in formal interviews or an informal discussion.
11. Select appropriate individual to partner with and plan working.
12. Complete delivery of process, or part thereof.
13. Evaluate the success of the partnership, both in terms of the work completed, the success of the relationship and the value added by having a co-researcher.

Resources required (including time)

- ❖ Significant staff time - to plan process, find suitable co-researcher, build relationship and run process
- ❖ Significant patient / public partner time – to be actively involved in the process
- ❖ Costs - recognition for involvement and payment of expenses

Significant risks and mitigation

- Value is not fully realised, despite high resource cost.
 - Be clear about purpose of patient co-researcher and desired value.
 - Evaluate rigorously after all efforts to involve in this way to develop learning.
- Quality of work is lessened because the relationship between co-researchers fails.
 - Ensure trust is built between both parties quickly.
 - Design a selection process that supports finding parties who can work well together.
- Co-researcher does not deliver to expectations.
 - Clear outline of expectations – role description is likely to be helpful here.
 - Define evaluation of co-researcher role together at the beginning.
- Governance protocols are not adhered to.
 - Co-researcher should sign all appropriate governance documentation.
 - Role description should include some description of importance of governance protocols.

Roles and responsibilities for staff

- ☐ Teams – identify opportunities where co-researchers could add significant value.
- ☐ Senior staff – agree support for co-researchers where identified.
- ☐ Individual staff – undertake applying this method in their work and report on learning.

Measuring impact

The impact here relates to the purpose of the involvement, the perceived value of the patient / public partner as an active contributor, the strength of the relationship built and the impact this has on wider ways of working in the directorate. It is suggested that evaluation in this area be tied into wider evaluation of activity across the directorate.

Further resources

[Lay involvement in the analysis of qualitative data in health services research: a descriptive study.](https://doi.org/10.1186/s40900-016-0041-z)
 Garfield, S., Jheeta, S., Husson, F. et al. Research Involvement and Engagement 2, 29 (2016).
<https://doi.org/10.1186/s40900-016-0041-z>

4. Frequently Asked Questions

4.1 How do we find patients or members of the public to involve or engage?

The most common way organisations find patients and members of the public is through other organisations and networks. Organisations that have access to patient groups include:

- Academic Health Science Networks
- Academy of Medical Sciences
- Applied Research Collaboratives
- Association of Medical Research Charities
- Biomedical Research Centres
- BMJ Patient Panel
- Clinical Commissioning Groups / Primary Care Networks
- Connected Health Cities
- Crick Institute
- Farr Institute
- Foundation Trust' Council of Governors and members
- Genomics England
- GP Practice Patient Participation Groups
- Health Data Research UK
- Healthwatch
- Healthcare Quality Improvement Partnership
- Integrated Care Systems
- Medicines and Healthcare products Regulatory Agency
- National agencies - NHS England / NHS Improvement / NHSX and related regional offices and structures
- National Voices and their member organisations
- NHS Trust patient involvement groups and Involvement Leads
- National Institute for Health and Care Excellence (NICE)
- NIHR's INVOLVE
- Online patient communities – including PatientsLikeMe and HealthUnlocked
- Other local or regional patient advisory groups – often relating to local/regional forum
- People in Research
- Public Health England
- Recruitment in clinics and through clinicians
- Richmond Partnership
- Royal Colleges
- Turing Institute
- Understanding Patient Data
- Use My Data
- Voluntary and community sector organisations and groups

This is not an exhaustive list. Working through non-health community organisations will also encourage greater diversity of perspective in your work.

4.2 What is the right number of people to involve?

There is variability in what is suggested as a minimum number of interviews in the social sciences, however guidance suggests between 12 and 16 is enough to identify common themes from relatively defined groups.

That said, it is not always possible to involve or hear from 12-16 patients and the public. In this respect, the PPIE community tends to work on the basis that any involvement and diversity in perspective may add value and shape and improve work and research.

There is a tension between time, resource and more varied perspectives that means more PPIE activity is done with fewer than 12 people.

Do not let perfection be the enemy of the good – it is absolutely possible for the involvement of just one person to influence and improve the work of the directorate but be aware of the potential for bias.

4.3 How do we ensure adequate representation?

Representation is tricky in PPIE but diverse perspectives, skills, experiences and backgrounds are essential. The key is to focus on what representation in the specific work looks like, rather than representation of the whole UK population in everything.

Moreover, it is essential to think about the involvement or engagement of seldom-heard communities. This is often, quite appropriately, thought about as those with protected characteristics or in vulnerable communities but if you were working on, for example, breast cancer, this could include men with the diagnosis.

It is important to think about representation early and often in planning involvement and engagement work, and work with and through organisations that can help you engage seldom-heard communities. Vary the PPIE approach depending on needs and cultural norms of that community and adapt as you go along. Meet them where they are, rather than expecting them to come to you.

In particular, work to find opportunities to hear family and carer perspectives.

4.4 What resources are required to undertake involvement or engagement work?

- Teams time to plan and agree PPIE work.
- Staff time to plan and enact PPIE in work.
- Leadership / consultant time to plan, monitor and evaluate PPIE work.
- Payment for expenses and recognition for involvement costs for patient / public partners.
- Other approach costs (e.g. venue, refreshment, partnership).
- Some organisations hire consultants and facilitators to support early PPIE activities.
- Many organisations recruit (at an organisational-level) full- or part-time PPIE staff to support PPIE work.

4.5 How do you manage expectations?

The expectations of patients and the public are often highlighted as a key concern for staff looking to involve. In particular, there may be concerns around people having unrealistic expectations around what can be achieved. Three actions will help to manage expectations:

- a. Work to understand the expectations of those you have involved or engaged at the beginning.
- b. Be as open and honest as possible about what is, or may be, achievable in work.
- c. Clearly communicate the purpose, desired output(s) and outcomes of the work throughout the PPIE.

Staff may also have unrealistic expectations about what patients and the public are able to contribute. Clear discussion around expectations, for both sides, will support greater trust between patient / public partners and staff. This will deliver better involvement.

Ensure you feedback to those involved or engaged on how insights have been used, even when nothing changes.

4.6 How do you build trust and relationships with patients and the public?

- Actively listen to their perspectives (before trying to persuade).
- Find things you have in common.
- Ask lots of questions.
- Understand and use 'what's in it for them' – why does this matter to them?
- Be aware of non-verbal communication and how you are projecting these.
- Be visible and consistent.
- Be an expert but don't always expect to have the answers.
- Talk 'we' not 'I'.
- Focus on outcomes not solely outputs - reflecting on why this matters collectively.

4.7 How do we make involvement or engagement work more accessible and inclusive?

This is one of the common themes those working in PPIE focus on. There are no simple answers. A number of actions should help support accessible and inclusive involvement and engagement:

- Using a variety of approaches to involvement and engagement.
- Going to people, where they meet, as well as hosting PPIE work.
- Seeking out defined-characteristic groups, organisations and networks for specific feedback and engagement.
- Being prepared to offer payment for a variety of expenses and flex to encourage inclusive involvement (as detailed below).
- Where PPIE work requires venues, seek spaces that are accessible for anyone whose mobility is limited and be prepared for adaptations around other requirements.
- Where refreshments are required, ask about allergies and any other dietary requirements.
- Involving or engaging those who have been affected by sight or hearing loss may require materials in braille, extra facilities and space for sign language translation, speech-to-text support, or guide dogs.
- Language – ensure that where you are working with partners in other nations, the language avoids English colloquialisms and, where appropriate, is translated (i.e. Welsh).

4.8 What expenses should we cover and how do we recognise the value people bring through PPIE?

There are two purposes to this – firstly to make involvement and engagement activities more accessible to a wider group by ensuring no one is out of pocket for getting involved; secondly to recognise that the perspectives people bring are valuable.

Travel and subsistence, where appropriate, expenses should be covered as part of standard policy. While public transport is the usual mode, some patients may require either their own car or a taxi to ensure they are able to participate. Ideally these will be paid upfront or covered in a way that does not leave patient or public partners out of pocket.

Accommodation, carer and childcare costs may also need to be included. Patient / public partners may have other expenses that need to be covered in order for them to be involved. A flexible policy works best in this.

The value added by patient / public partners is increasingly recognised through an offer for time spent. This is considered best practice in both health services and health research for significant commitment. On the whole, activities that engage a larger group of patients are not included in this but activities that involve a smaller number, often 1:1 or where there is active involvement in delivery, will be offered a sum.

In order to avoid problems with benefits, offers may be given as vouchers as well as payment. If patient partners are receiving state benefits, any payment of fees may affect their benefit claim. In relation to this and other matters, you may find it useful to refer to [INVOLVE's payment and recognition for public involvement](#) website.

There is significant consistency from national (and other) organisations on the rate. This is typically offered as £75 per half day, £150 per day, and takes travel and reading time into account.

5. Evaluating impact of patient and public involvement and engagement

Evaluating the impact of PPIE at directorate level should focus on the purpose of that involvement and engagement - working towards the desired outcomes of:

1. Improving research.
2. Supporting directorate strategy and planning to take account of what matters to the public.
3. Working to shape policy that improves health and care for communities.
4. Improving how we involve and engage patients and the public in the longer-term.

These are, however, longer-term outcomes. While each guide include some reflections on shorter-term evaluation, there are ways to evaluate wider efforts and longer-term work. The [GRIPP2 checklists](#) provide a short-form and long-form tool for reporting patient and public involvement in research. While the topics covered relate to reporting, these tools are useful guidance in monitoring and evaluating the impact of PPIE.

Monitoring PPIE work is going to be an important part of evaluation. To this end, a short survey, along the lines of the GRIPP2 short-form tool, that asks staff who have led PPIE work about the approach used, costs (including time), value of insights through the involvement, and what, if anything, changed because of the involvement could be helpful. This could be circulated after activity is completed or more widely on a regular (3-6 month) basis.

It is important to also collect patient / public partners feedback on being involved in the process. This is included in the specific approaches above but there is likely also work to do in understanding their perceptions of PPIE in the directorate. This could be done every 6-12 months.

Potential process metrics

- Number of patients, carers and public involved in the work of the directorate.
- Organisations worked with and through to undertake PPIE.
- Number of projects where PPIE activity has taken place.
- Types of PPIE activity (approaches used) in projects.
- Number of opportunities to communicate work with public audiences (includes written).
- Directorate-level PPIE activity.
- Perceived quality, usability and value of insights gathered through PPIE.
- Staff confidence to undertake PPIE activities.
- Staff knowledge of where to find resources and support for PPIE work.
- Requests for support to undertake PPIE activities.

Resources required

- ❖ Senior staff – time to agree, plan, monitor and undertake wider evaluations.
- ❖ Staff – time to fill in any circulated surveys about activity and impact.
- ❖ Patient / public partner – time to fill in any circulated surveys about activity and impact.

Significant risk

- Evaluating PPIE activity takes too much time and effort and either takes too much focus or does not get done.
 - Keep evaluation simple and focused on the desired outcomes and purposes.
 - Communicate the learning from evaluation internally and externally.
 - Plan for measuring impact from the beginning and build into wider PPIE processes.



Better public involvement for better health and social care research

INCLUSIVE OPPORTUNITIES

Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

WORKING TOGETHER

Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

SUPPORT AND LEARNING

Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

COMMUNICATIONS

Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

IMPACT

Seek improvement by identifying and sharing the difference that public involvement makes to research.

GOVERNANCE

Involve the public in research management, regulation, leadership and decision making.

Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research

The International Journal of Population Data Science; Vol. 4 No. 1 (2019)

“Our key premise is that the public should not be characterised as a problem to be overcome but a key part of the solution to establish socially beneficial data-intensive health research for all.”

“This consensus statement reflects the deliberations of an international group of stakeholders with a range of expertise in public involvement and engagement (PI&E) relating to data-intensive health research. It sets out eight key principles to establish a secure role for PI&E in and with the research community internationally and ensure best practice...Our aim is to promote culture change and societal benefits through ensuring a socially responsible trajectory for innovations in this field.”

“This consensus statement is intended to be used in a reflective way to guide practice as the field evolves...We invite people to reflect on this when discussing PI&E in data-intensive health research and engage with us to promote best practice locally, nationally and internationally.”

Members of the Farr Institute Patient Panel were involved in its development.

Public Involvement and Engagement in Data-Intensive Health Research Requires Special Consideration⁵

- Given the scale of data-intensive health research, involving data from large numbers of people and populations, PI&E is particularly important for awareness raising and for enabling people to participate in processes of research and governance.
- PI&E is particularly important to bridge the gap between data scientists and the people to whom the data relates.
- As well as bridging a gap between researchers and the people to whom the data relates, PI&E can also be a mechanism for bridging a gap between the public and the data about them.
- Given that data are often used and linked without individuals' explicit consent, PI&E has an important role to play in establishing a social licence for current and future practices.
- Data-intensive health research can promote and enact PI&E to address wider science society relations.

Key Principles for Public Involvement and Engagement in Data-Intensive Health Research⁶

PI&E relating to data-intensive health research should:

1. Have institutional buy-in
2. Have clarity of purpose
3. Be transparent
4. Involve two-way communication
5. Be inclusive and accessible to broad publics
6. Be ongoing
7. Be designed to produce impact
8. Be evaluated

⁵ <https://ijpds.org/article/view/586>

⁶ <https://ijpds.org/article/view/586>

Resources

Links

Access to Understand. [Promoting Understanding of Biomedical Research](#) – Guidance

Cancer Research UK. [Patient involvement toolkit for researchers](#).

Diabetes UK. [Patient and public involvement \(PPI\) in your study](#).

Imperial College London, Faculty of Medicine. [Public Involvement Resource Hub](#).

Imperial College London. [Patient Experience Research Centre](#).

James Lind Alliance. [Priority Setting Partnerships](#).

National Co-ordinating Centre for Public Engagement. [What is public engagement?](#)

NHS England. [Bitesize Guides to Participation](#).

NIHR. [PPI \(Patient and Public Involvement\) resources for applicants to NIHR research programmes](#).

NIHR Guy's and St Thomas' Biomedical Research Centre. [Patient and Public Involvement toolkit](#).

NIHR Involve. [Resources](#).

NIHR Oxford Biomedical Research Centre. [PPI Resources for Researchers](#).

NIHR Research Design Service London. [Patient and Public Involvement Resources](#).

[Patient Information Forum](#)

[Plain English Campaign](#).

[Public Involvement Impact Assessment Framework](#) (PiiAF).

UCL Centre for Co-production in Health Research. [Blog](#).

Understanding Patient Data. [Supporting conversations](#).

Journals

[Research Involvement and Engagement](#)

[Health Expectations](#)

[Patient Experience Journal](#)

Reports

[Going the Extra Mile – NIHR Strategy for Patient and Public Involvement \(2015\)](#)

[National Standards for Public Involvement, NIHR \(2019\)](#)

Relevant articles

Ocloo J, Matthews R. [From tokenism to empowerment: progressing patient and public involvement in healthcare improvement](#). BMJ Quality & Safety 2016;25:626-632.

Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. [GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research](#) BMJ 2017; 358 :j3453