

Involving patients and the public in research

Sonja Marjanovic
Amelia Harshfield
Asha Carpenter
Adam Bertscher
Daniel Punch
Sarah Ball



Contents

- 1 Background
- 1 Approach
- 2 Why do patients and the public get involved in research?
- 3 How are patients and the public involved in research?
- 5 What enables patients and the public to get involved?
- 6 What challenges prevent or hinder involvement, and how can they be overcome?
- 8 What is the impact when patients and the public get involved in research?
- 10 Areas of focus
- 11 Conclusions
- 11 Acknowledgements
- 11 Further reading
- 12 References

Authors

Sonja Marjanovic, RAND Europe
Amelia Harshfield, RAND Europe
Asha Carpenter, RAND Europe
Adam Bertscher, RAND Europe
Daniel Punch, The Healthcare Improvement Studies Institute
Sarah Ball, RAND Europe

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Background

Patient and public involvement (PPI) has become increasingly widespread in research about healthcare. Over the past few decades, there has been growing recognition in research circles that people with lived experience can and do make important contributions to studying healthcare, and that there are morally rooted reasons to involve them. Today, PPI is an integral part of how research is done in the UK. Research funders, charities, and healthcare organisations have integrated PPI into their policies and working cultures,^{1,2} and have made significant investments into regional and national infrastructures to support involvement. Practical guidelines on how to do PPI have also been published, and a body of academic literature about PPI is emerging. Yet PPI remains a relatively new field of enquiry, leaving questions about when, why, and how patients and the public can best be involved in research.

One challenge in answering these questions is that the impacts of PPI on the research process, research outcomes, and the people who get involved are often not evaluated. There are also concerns that what is advocated as good PPI practice isn't always feasible, and that PPI can sometimes become a tick-box exercise.

This learning report aims to build a better understanding of the role of PPI in research, thereby helping ensure meaningful involvement that has tangible impacts and mitigate against undesired consequences.

Approach

To inform this learning report, we conducted a rapid review of relevant academic and grey literature published between the years 2000 and 2018. The insights gained from this review were complemented by interviews with experts in the field, including people from organisations that involve patients and the public in research and those that provide guidance on how to do so effectively. We also interviewed people who research PPI, patient representatives, and people who work in organisations advocating for patients. Our expert interviewees included:

- Prof Roger Barker – Professor, University of Cambridge
- Dr Jo Ellins – Health Services Management Centre Senior Fellow, University of Birmingham
- Dr Jane O'Hara – Senior Research Fellow, Associate Professor, University of Leeds/Bradford Institute for Health Research
- Beccy Maseo – Senior Research Manager, James Lind Alliance
- Richard Stephens – Consumer Lead, National Cancer Research Institute (NCRI)
- Jeremy Taylor – former Chief Executive, National Voices
- Caroline Whiting – James Lind Alliance

It is worth noting that distinctions are sometimes made between 'involvement', 'engagement' and 'participation' in research (eg by the National Institute for Health Research's (NIHR) INVOLVE advisory group). However, these distinctions are often blurred in the literature,³⁻⁹ particularly in applied health research and health services research. Many systematic reviews of PPI activities note the challenges they faced finding relevant literature, in part because PPI lacks standard terminology.¹⁰⁻¹²

For the purposes of this report, we make a distinction between active 'involvement' and 'engagement', like shaping research questions and analysing data, and study 'participation', like being interviewed as part of a research project. Our review was particularly concerned with active involvement.¹³

Though PPI is increasingly common in healthcare research, there is limited agreement about how, when, and why it should best be done.

While this report provides a wide-ranging reflection on PPI approaches, challenges and enablers, it is important to note that many papers we reviewed lacked detail about PPI activities and were often based on opinion rather than validated measurement.⁵ Formal requirements to report the PPI methods used in a particular research project are often lacking, and we found that few studies evaluated the fidelity of their PPI approaches, making it difficult to know whether the approaches discussed were implemented as intended.

More details about the study design and methods are available in the full source report by RAND Europe at www.rand.org/pubs/research_reports/RR2678.html

Why do patients and the public get involved in research?

Reasons why patients and the public get involved

Our findings showed that patients and the public get involved in research for a number of reasons, influenced by their diverse life experiences, interests, and prior involvement with healthcare and research. These include:

- wanting to help others^{6,14-17} and contribute to a better healthcare system³
- wanting patient perspectives to be reflected and have influence in research and ultimately on healthcare^{6,18,19}
- interest in research and in contributing to scientific knowledge^{15,17-19}
- interest in the healthcare topic, often because of personal experience^{6,15,18,19}

Altruistic reasons like helping others and giving back to the community were common motivators,^{6,14-17} as was the belief that PPI can make research more meaningful for patients¹⁸ and facilitate tangible impacts to healthcare services.²⁰ As one interviewee described it:

“There is no good for [patients] to get involved if it [the research] results in loads and loads of brilliantly argued academic articles ... and researchers presenting at conferences in Chicago or Lake Lugano ... we want to know what happens to the patients ... has that [the research] actually changed clinical practice...”

Reasons why researchers involve patients and the public

Researchers involve patients and the public in research for diverse reasons, many of them consistent with the reasons patients and the public get involved. They may believe that PPI is the right thing to do,^{7,15,21} or that it will improve research outputs,²⁰ or they may have had a positive prior experience with PPI.¹⁵

Researchers also have more pragmatic reasons for involving patients and the public. For example, PPI may be a condition of research funding,^{1,15,19,22,23} a response to a policy imperative,²⁰ or a way to help recruit and retain study participants.^{19,21}

How are patients and the public involved in research?

Getting involved can mean different things depending on the person, the project, and the type of research.

Table 1 provides examples of the various tasks patients and members of the public undertake as part of research projects.

Though these tasks span all phases of research,^{20, 22-26} the literature indicates that higher levels of PPI are often reported during the set-up phases than during later phases like data collection, analysis,^{15, 23} dissemination and translation.^{12, 15, 22}

How long and how often patients and the public are involved varies from project to project,^{19, 27} but long-term PPI is rarely reported through the entire research lifecycle. In one review of nearly 200 studies related to patient-reported outcome measures for chronic disease and quality of life, only 10 per cent reported involving patients throughout the duration of the research.²⁷

Patients and the public get involved in research for a variety of reasons but often because they want to help others and contribute to a better healthcare system.

Table 1 Research activities undertaken by patients and the public

Research stage	Tasks and activities
Agenda setting	<ul style="list-style-type: none"> Identifying or generating research topics or questions^{23, 24} Prioritising topics for research^{10, 21, 24, 26, 28} Developing patient-relevant commissioning briefs²⁴ Providing a patient perspective on outcomes that are important to patients and their families, eg through participating in patient-centred outcomes research²⁸⁻³⁰
Funding	<ul style="list-style-type: none"> Providing input into funding decisions^{21, 26} Contributing to the development of research proposals/funding bids^{9, 26, 28, 31} Reviewing research proposals^{26, 28}
Design and procedures	<ul style="list-style-type: none"> Advising on development of surveys and interview guides with respect to accessibility of language, question relevance and appropriateness, or acceptability of format and timings^{4, 5, 8, 9, 15, 18, 20, 24} Advising on scope and/or search strategy for reviews^{7, 24, 31-33} Advising on the feasibility of conducting research in real-world settings in relation to type/timing of interventions²⁶ or identifying cultural issues that need to be considered²⁴ Advising on variables/outcomes that matter to patients/public^{24, 26, 30, 32} Advising on sampling^{4, 18, 26} Advising on ethical issues such as consent processes^{11, 24, 30} Developing patient information materials^{5, 15, 20, 23, 24, 30} and study websites²⁶
Recruitment of study participants	<ul style="list-style-type: none"> Advising on recruitment/troubleshooting recruitment difficulties^{4, 5, 15, 24, 26} Identifying or assisting with access to potential research participants^{7, 24} Developing participant recruitment materials³⁴ Actively engaging in participant recruitment activities^{11, 15, 20, 22} Advising on how to maintain adherence/continued participation²⁶
Data collection	<ul style="list-style-type: none"> Contributing to the conduct of literature reviews by locating relevant literature, screening and extracting or coding articles^{11, 31, 32, 35} Collecting data from research participants by conducting interviews, administering surveys, co-facilitating focus groups^{9, 22, 24} Co-generating data with researchers on topics of interest through participatory methods²⁰ Contributing to management of data collection (eg by tracking participant visits)²²
Data analysis	<ul style="list-style-type: none"> Actively conducting data analysis tasks (eg coding interview transcripts in qualitative studies)^{3, 9} Contributing to data analysis by guiding or identifying themes²⁴ in both reviews^{11, 24, 35} and qualitative studies^{4-6, 9, 31} Co-analysing with researchers through participatory action learning²⁰ Adding patient perspective to the synthesis and interpretation of findings^{14, 22, 24, 32} Highlighting key findings^{11, 18, 31} Contributing to development of practice recommendations^{12, 31}

Table 1 Continued

Research stage	Tasks and activities
Dissemination	<ul style="list-style-type: none"> Contributing to drafting journal articles/reports/reviews^{4, 9, 22, 23, 28, 32} Critically reviewing articles/reports^{3, 5, 6, 8, 11, 23, 28} Producing or co-creating accessible outputs on study findings, such as plain language summaries,^{8, 11, 23, 26, 28, 35} participant newsletters/results communication,^{16, 22} infographics¹¹ or webinars¹⁸ Delivering or co-delivering presentations at conferences^{9, 22, 24, 28} or project dissemination events⁹ Participating in the release of results or publications¹⁹ Determining avenues to share findings²²
Facilitating uptake	<ul style="list-style-type: none"> Contributing to clinical guideline development – question development and development of plain English questions³⁶ Preparing decision aids for patients²⁸
Evaluation of research	<ul style="list-style-type: none"> Providing feedback on experience as a PPI contributor as part of an evaluation of PPI for a specific project^{9, 22, 31} Participating in research on the topic of PPI^{3-9, 17}

What enables patients and the public to get involved?

The increased focus on PPI in research has led to the development of mechanisms that support and enable involvement, summarised in **Table 2**. At the governance level, they include funding PPI activities appropriately and clearly defining PPI roles. Providing user-friendly, supported ways to get involved can also help encourage involvement, as can providing training and mentorship for PPI contributors and researchers. Citizen science, which empowers people from diverse backgrounds to contribute to research, is one innovative approach that could potentially provide this support.

Research organisations can enable involvement by making clear how they use and value the input received from PPI and committing to providing feedback to contributors.

People who get involved want to know how their contributions were used and how they made an impact^{4, 12} and are keen to be acknowledged for it in some way – be it through a simple ‘thank you’ or through more formal recognition.^{8, 37}

People who get involved in research tend to value learning and personal development,^{6, 15, 17-19} social relationships and networks, and the sense of contributing to something bigger.^{6, 16} According to one research participant, “Rewards come from the sense that you have made a meaningful contribution.”

Financial compensation was also identified in the literature, though it was not among the most valued forms of recognition.^{6, 7, 11, 19, 36} Interviewees noted that sometimes contributors may need upfront payment.

To enable involvement, PPI needs to be funded adequately, opportunities need to be clearly communicated, and support needs to be available for researchers and PPI contributors.

What challenges prevent or hinder involvement, and how can they be overcome?

Challenges

Despite growing awareness of mechanisms that enable PPI, evidence suggests that a number of challenges remain. PPI is not always funded appropriately or evaluated effectively, and learning isn't always shared in a coordinated way. Values and attitudes about PPI can sometimes hinder involvement, for example, if researchers are dismissive about PPI or only include it in a tokenistic way. Researchers also face a scarcity of established and validated frameworks to guide effective PPI.^{11, 27}

For patients and the public to get involved in research, they need to be aware of the opportunities that exist – and raising awareness can be challenging. They may also lack access to training that would facilitate effective engagement or face challenges related to their health. People thinking about getting involved may lack the confidence and experience to do so, while those who do get involved may risk becoming over-professionalised and losing their lay person perspective.¹⁵

Representativeness is another area of concern in PPI. Researchers often strive to ensure PPI contributors collectively reflect the diversity of society in line with the needs of the research project, but it can be difficult to achieve.

How to overcome them

Many of these challenges are deeply rooted, and overcoming them will mean changing cultures, structures, attitudes, and expectations. Two of the experts we interviewed highlighted how avoiding the risks of tokenism and pursuing diversity among contributors, for example, will require a shared understanding about what constitutes meaningful involvement for each project, and a balance between the ideal solution and the feasible one. Working with community partners and networks, making opportunities accessible, and drawing on online tools like crowdsourcing to reach more people could potentially help PPI activities better reflect the diversity in society.

Funding issues can be addressed if health systems can ensure enough money is available to support the scale and nature of PPI that stakeholders may wish to pursue. Developing an infrastructure that can bring together the currently fragmented information about opportunities to engage could also help raise awareness.

Other challenges might be addressed by more straightforward solutions, like having clear and documented agreements on PPI roles between researchers and PPI contributors, using practical tools like language glossaries, and developing infrastructures to provide feedback to PPI contributors.

Doing PPI just for the sake of it can discourage researchers and disenfranchise people who get involved. PPI should be relevant and meaningful for the research and the people involved.

Table 2 PPI challenges and enablers

Driver of effective involvement	Challenges	Enablers
Governance, management and infrastructure	<ul style="list-style-type: none"> • Inappropriate financial resourcing for PPI^{2, 3, 7, 8, 11, 23, 24, 32, 38} • Poor reporting on PPI processes and limited monitoring and evaluation^{11, 20} • Little coordination and shared learning between different PPI bodies²⁷ • Lack of a common definition of PPI leading to confusion about what it entails^{20, 39} • Limited patient and public awareness about involvement opportunities² • Recruitment and retention strategies based on insufficient understanding of what motivates PPI contributors^{15, 23, 29} • Lack of clarity on PPI contributor roles • Lack of built-in feedback mechanisms^{3, 6, 11} • Administrative challenges related to limited support capacity, administration costs and/or system bureaucracy^{2, 11, 22, 23, 38} • Mandating PPI in the absence of evaluation, leading to tokenism 	<ul style="list-style-type: none"> • Ensuring sufficient resources for PPI activities⁸ • Managing financial reimbursement or upfront payment for PPI contributors effectively^{2, 6, 7, 11, 19, 36} • Clearly specifying the goals of PPI in projects and being clear about contributor roles^{3, 4, 8, 12, 14, 15, 31, 40} • Involving patients early on in research design to build a sense of shared ownership^{5, 8, 15} • Establishing mechanisms to nurture relationships throughout a project or initiative • Having flexibility in timing of engagement and in how contributions can be made^{7, 37, 6, 21} • Creating user-friendly online platforms (eg well-designed, relevant and engaging online websites and portals)^{7, 37, 6, 21}
Individual and organisational capacity	<ul style="list-style-type: none"> • Ineffective communication that uses scientific language and jargon^{8, 21, 23, 31} • Lack of experience, knowledge, skills or confidence among PPI contributors⁸ • Risks of overprofessionalising PPI and losing lay perspectives¹⁵ • Challenges to representativeness among contributors^{3, 6, 7, 14, 17, 22, 23, 38} • Challenges relating to individual health or wellbeing (eg inability to travel)^{15, 22, 23} 	<ul style="list-style-type: none"> • Training and supporting PPI contributors on how to effectively engage with research^{2, 6, 21, 41} • Training researchers on how to conduct effective PPI^{2, 7, 8} • Designating leadership for PPI within research organisations^{2, 32}
Culture, attitudes and behaviours	<ul style="list-style-type: none"> • Tokenism that impedes the implementation of PPI approaches and their integrity^{1, 8, 11, 20, 23} • Dismissive attitudes among some researchers^{2, 3, 7, 8, 11, 15} • Public and patient reservations about their ability to influence⁸ • Challenges for researchers in managing expectations of PPI partners (eg about roles and goals)²³ • Managing group dynamics (eg power-dynamics between researchers and PPI contributors, and between individual members of PPI groups)^{12, 32} 	<ul style="list-style-type: none"> • Receptive researcher attitudes to PPI^{6, 8, 18, 21} • Openness among PPI contributors to views other than their own⁸ • Investment in collaboration and co-learning^{2, 6, 9} • Commitment to providing feedback on how an individual has impacted on research, study progress, results and impacts^{4, 12, 16} • Acknowledging and recognising contribution (eg with rewards)^{2, 8, 37} • A commitment to learning through PPI evaluation⁹ • Mechanisms to enable connected PPI contributor communities⁶

What is the impact when patients and the public get involved in research?

Positive impacts

Our review identified a number of potential positive impacts of PPI, including benefits for the people who contribute, the research study, and the wider research system. For PPI contributors, potential impacts include a sense of empowerment, learning new skills, and the rewarding experience of giving researchers a new perspective on their work. In terms of potential impacts on studies, PPI can make research more relevant by shaping research priorities, helping with study participant recruitment, and ensuring findings are disseminated in accessible ways. At the system level, PPI can potentially ensure research funds are spent more accountably and that research fits with moral obligations, values and norms. A fuller list of the potential impacts of PPI is covered in [Table 3](#).

The literature we reviewed also highlighted some examples of this potential being realised in practice. For example, in the case of one UK initiative aimed at involving cancer and palliative patients and carers in research, PPI helped identify and prioritise research topics that matter to patients, made research more relevant and accessible, and helped foster links between researchers and the community.⁴² In another example, the James Lind Alliance (JLA) – which brings together patients, carers and clinicians to identify priority areas for research – has reported various positive impacts from involving patients, the public, and other stakeholders.⁴³ Participating patients reported that they felt empowered and fulfilled from contributing to something worthwhile.^{44, 45}

But beyond these specific cases of assessed impacts, the evidence base for actual impacts of PPI is piecemeal and inconclusive. Many studies focused on PPI's potential, reporting assumptions or perceived impacts^{1, 2, 4, 10, 12, 34} rather than evidence from evaluations. This is by no means unique to PPI; there are also challenges to evaluating the impact of other stakeholder groups. Our findings about impact are consistent with those of a similar review on involving NHS staff in research,⁴⁶ and may reflect larger challenges identifying and evaluating impact in the broader research community.

Unintended consequences

Most studies tended to report on positive impacts – actual or potential – but we also identified some unintended consequences of PPI. In one initiative in Canada, for example, researchers used a community-based approach to collaborate with members of the public to design studies on improving services for low-income families. This led to delays and caused strained relationships between collaborators.⁴⁷

When PPI is not done well, patients can be left feeling that they are not valued or listened to.^{2, 14} On the other side, researchers who feel they are mandated to involve patients and the public even when they do not see the value of involvement, and perhaps when it is not appropriate for the project at hand, may lose motivation and end up being tokenistic about PPI.²

The question of evaluation

As noted above, our review found little evidence about the impact of PPI. But that does not mean PPI has little impact.⁸ Instead, it suggests a lack of high quality evaluations of the impact of PPI activities.

Should PPI therefore be evaluated in all circumstances? Some have argued that patients and the public should be involved regardless of their impact, because their involvement makes the research process more democratic and is 'the right thing to do'.^{9, 48} Others say that the plethora of PPI activities now in place, and the fact that support for PPI activities often flows from publicly funded research bodies, make a clear justification for evaluation. Our review suggested that PPI can help us learn about how to improve future PPI efforts,⁹ ensure PPI methods are replicable, and contribute to the wider evidence base on the impacts of PPI in research.

But evaluating PPI more thoroughly and consistently may be easier said than done. Evaluation in this area is recognised as methodologically challenging,⁸ with relatively few established and validated frameworks to support PPI evaluation²⁷ and inconsistent reporting on PPI activities.^{20, 24} To evaluate PPI effectively, it is important to be clear about what PPI is expected to achieve, how quality should be evaluated, and how impact should be assessed. Some agreement is also needed on the types of PPI impact that are worth measuring, and what sort of study designs are appropriate. So far, these questions have been contentious.¹

Table 3 Potential impacts from patient and public involvement

Type of impact	Examples of potential impacts
Impact on individuals	<ul style="list-style-type: none"> • Helping PPI contributors by empowering them to engage in research and collaborate with other stakeholders, building their confidence, helping them learn about a health topic and about research, making them feeling valued, or improving their access to information about how to manage a condition^{3, 6, 10, 11, 20, 24, 33} • Helping researchers by building their understanding of the public/community perspective to healthcare, building their understanding of the population who may benefit from the research, and making them feel more purposeful and better connected to those beneficiaries^{2, 10, 18, 20}
Impact on research studies	<ul style="list-style-type: none"> • Prioritising research topics in a way that better reflects what matters to patients^{2, 9, 10, 14, 22, 37} • Solving ethical dilemmas⁴ and informing consent processes efficiently and effectively^{11, 14, 48} • Contributing to more patient-focused study designs to enhance relevance for patients^{14, 18, 22, 23} • Informing study design and methods including research questions and objectives, research methods and protocols, research schedules, and the planning of data analysis^{2, 9, 11, 14, 19, 22, 23, 48, 49} • Facilitating better-quality research conduct informed by a more nuanced understanding of patient and public perspectives and needs^{2, 18, 23, 33} • Expanding the potential applicability of research by helping reach hard-to-reach populations and making the study more acceptable to the public³³ • Informing effective participant recruitment strategies and helping with recruitment during research implementation by providing access to participants and increasing public acceptability and understanding of a study^{2, 4, 5, 9-11, 14, 19, 20, 22, 49} • Impacting how data is collected or analysed^{4, 11, 22, 48} by contributing practical problem-solving skills and adding additional perspectives¹¹ • Convincing researchers to persist with a study in the face of challenges and contributing ideas for follow-on work¹⁹ • Enabling a better experience for study participants by ensuring that participants are better informed about a study and better prepared to contribute^{3, 6, 19, 31} • Ensuring that a user perspective is reflected in how data is interpreted and meaning is constructed¹⁴ • Improving communication with patients and the public for example by actively engaging in dissemination^{4, 10, 48} and making the study and its results more accessible for patients and the public^{4, 19} • Increasing the likelihood of translation and uptake of research findings in practice^{2, 18, 33}
Impact on the wider research system	<ul style="list-style-type: none"> • Increasing accountability regarding the use of public funds by researchers³³ • Improving access to research funding¹¹ • Aligning research practice with the perceived moral obligations of researchers³³ including by reducing power imbalances and increasing mutual respect and trust between the research and patient communities^{11, 24}

Areas of focus

Based on what we learned from the rapid evidence assessment and interviews, we offer some recommendations for organisations to consider when developing PPI strategies. They are not prescriptive in nature. Instead, they are intended to open discussion and encourage further dialogue.

Meaningful involvement doesn't mean involvement in everything

PPI should be relevant and meaningful for the research and the stakeholders involved, and guided by an involvement strategy grounded in values. Avoid making PPI a 'must-do in all circumstances' or carrying it out in a generic, tick-box fashion. In the words of one interviewee:

"It is easy to fall into trap of having to engage everyone in everything. There is a need to prioritise ... you don't want to tie up lots of people's time in activity that might not be high value. Be thoughtful about purpose and priorities."

Think carefully about who to involve and why

The right contributors are the ones who help achieve the desired impacts of PPI, and they can be very different across projects, tasks, and organisational activities.

Consider what motivates patients and the public when recruiting for PPI

Communicate the opportunity to get involved in a compelling and accessible way, highlighting the importance of the research and its potential impacts on the health system.

Use a mix of approaches to recruit and raise awareness

Consider online and offline mechanisms that engage directly with individuals, organisations and communities, or go through intermediary organisations and system stewards. Web-based platforms can help reach beyond the 'usual suspects', but are rarely the only mechanisms for raising awareness about involvement opportunities.

Work together, build collaborations and develop a coordinated approach

Researchers, funders and policy makers can work together to raise awareness about involvement opportunities. Building an infrastructure which supports local and national involvement across the healthcare system could help reach a broader range of individuals.

Make PPI roles clear from the outset, and communicate them in accessible language

Be proactive in building a shared understanding of PPI roles. It is important that these roles are developed jointly between researchers and contributors to help manage expectations.

Inform and support patients and the public who get involved

Provide accessible background information about the project and PPI roles, be transparent about the goals and expected outcomes, and ensure contributors get training, if needed. According to one person we consulted:

"Some people will need training and support to participate. If it's not [in place], then a lot of people will just self-select out of it as they will think that they don't have the right skills and that no one will support them."

Monitor and evaluate PPI activities to learn from the experience

Establish an evaluation plan at the outset of each research programme that highlights the desired impacts, the process for engaging patients and the public, and the methodology to be used in the evaluation. The plan should be clear whether it is evaluating the quality of the PPI process, its outcomes and impacts, or both.

Report on PPI methods in resulting publications

Describe who was involved, how, and what the outcomes were. This can ensure the methods are replicable and contribute to the wider evidence base on the impacts of PPI in research.

PPI has the potential to improve research and empower contributors, but evidence about how that actually happens, to what extent, and to what effect, is limited.

Conclusions

The increased focus on PPI in recent years has led to a proliferation of activity to support involvement. New PPI-focused panels and committees have been formed, infrastructure has been built, and researchers are routinely asked: “what are your plans for PPI?”

Patients and members of the public are now getting involved at all stages of the research process, in various ways and to varying degrees. And with their involvement comes a number of potential positive impacts for research, for the health system, and for them personally.

Yet amid this increase in PPI activity, a number of questions remain unanswered about how, when and why patients can best make meaningful contributions to research. Some have assumed the more PPI, the better, suggesting that co-production – the most involved of PPI approaches – is the ‘gold standard’. Others reject the idea of ‘the more, the better’, raising concerns that it may lead to tokenistic practice or work against meaningful involvement. The literature suggests there is value in a measured and customised approach to PPI based on the needs of the project. Doing PPI just for the sake of it, or bolting it onto already-agreed agendas, risks having unintended consequences.

Researchers need to confront the dangers of tokenism and be clear about the expected impacts of PPI – both for the research and the contributors. PPI also needs to be monitored and evaluated to understand the impacts and build an evidence base about what works, what doesn’t and why.

Enabling meaningful involvement requires understanding why patients and the public get involved in the first place, and committing to supporting them, valuing them, and giving them feedback about how their efforts shaped the research. It also requires all sides to be realistic about what approach to PPI is feasible and will add value.

To monitor and evaluate PPI, researchers will need to agree on what study designs are appropriate, be clear about what PPI activities are meant to achieve, and focus evaluations on the process of PPI and/or its contributions to research.

No single, shared understanding about when, why and how PPI should be done has yet emerged. And perhaps no such single understanding will exist in the near future. Patients and the public are diverse, as are the topics of research, and so taking a one-size-fits-all approach rarely works. But with careful consideration of when to do PPI, in what capacity, and toward what end – for the research and for contributors – all sides can benefit from bringing real-world understandings into research about healthcare.

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Further reading

This learning report provides an overview of research conducted by RAND Europe on behalf of THIS Institute. For more information about the study scope, methods, and findings, please consult the full source report, available at www.rand.org/pubs/research_reports/RR2678.html

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School of Clinical Medicine
University of Cambridge
Cambridge Biomedical Campus
Hills Road
Cambridge CB2 0AH
+44(0)1223 761841
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