Toolkits Mountain

How we scaled a mountain of guidance on patient and public involvement, and what we saw from the top.

Patient Experience Library

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1. Base camp

Quantity vs Quality

Patient and public involvement (PPI) is easy to talk about but hard to do. So an industry has evolved, in which multiple organisations churn out guidance on how to do PPI well.

It seems, however, that nobody has an overview of all the guidance that is being produced. There are large areas of duplication, and big gaps – especially when it comes to those communities that find it hardest to get heard.

Many people are keen to explain how PPI can be done well. Not so many are looking at how their own guidance could be better.

Here, we show what the PPI toolkits mountain looks like. We suggest some ways to get better value from the production of PPI guidance, and to make it more inclusive. And if you are a user of PPI guidance, you can skip straight to our interactive map to quickly and easily find the toolkit you need.

Big gaps

2. A clouded terrain

A lack of consensus

Patient and public involvement (PPI) is, these days, a given in healthcare policy and practice. Providers, commissioners, policymakers and researchers all state the importance of hearing from service users about what matters to them.

But what is PPI? It is hard to know because the terminology is confusing. Words like involvement, engagement and participation are used interchangeably, along with co-design, co-production and co-creation.

Some observers have commented that "There is no single formula for co-production"[1] and that "there is limited agreement about how, when, and why [PPI] should best be done"[2]. Others have noted a tendency to get bogged down in "semantic intricacies" and "circular debates held primarily amongst academics".[3]

It seems that we can agree that PPI is important, while being unable to agree on what it actually is.

Problems with practicalities

The confusion over definitions of PPI follows through into confusion over practicalities: "Lack of clarity on what PPI is (or might be) has given rise to a poorly monitored, complex field of activity"[4].

Basic rationales are also unclear. One study concluded that "published literature offers a complex and confusing picture about the underlying rationale for involvement practice"[5].

On top of all that, it can be hard to know what PPI actually achieves: "Certain kinds of impact, such as how do public involvement activities change power relations and empower the public, are largely not being captured"[6].

Somewhere, it seems, are the sunlit uplands of good involvement practice. But the way to them is shrouded in fog.

3. Sherpas for hire

A gaggle of guidance

Difficulties with definitions and practicalities in patient and public involvement open up a policy/practice gap. A great many organisations have rushed to fill this gap with advice on good practice in PPI.

Like the terms used to describe PPI (involvement, engagement, etc.), the words used to describe good practice advice are many and varied. Advice notes can be described as guidelines, frameworks, checklists, toolkits and more.

A lot of this material is being produced. A study led by Professor Trish Greenhalgh found over 60 PPI frameworks "drawing on different principles, applying different theories and prioritizing different potential use cases".[7] The authors noted that "developing a new framework from scratch was almost certainly unnecessary".

We were struck by that figure of over 60 PPI frameworks. Could there really be that many? If so, who was producing them all? And what, specifically, were they supposed to help with?

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4. The toolkit mountain

The search for the summit…

We decided to go looking for PPI toolkits. What we found staggered us.

The Greenhalgh study[8] had found over 60 PPI frameworks. We found 536.

Have we, in mountaineering terms, "summitted"? The honest answer is that we don't know. There could be yet more guidance still to be discovered. But the toolkit mountain is certainly much bigger than we had imagined.

…and what we found when we got there

536 toolkits is a vast landscape of guidance, and we wondered how to make sense of it all.

Our starting point was to look at when the documents were published. The earliest was from the year 2000. For the years up to 2009, we have fewer than 10 documents per year. After that, it explodes.

In a ten-year period between 2012 and 2022, PPI toolkits were being published at an average rate of one every two weeks. In the five years between 2016 and 2020, they were coming out at the rate of one a week.

We wondered how PPI professionals were meant to keep up. Luckily, Greenhalgh and her colleagues had already answered that question. They found that "most published frameworks have been little used beyond the groups that developed them".

So PPI frameworks and toolkits are being produced on an industrial scale. The extent of their use, however, might be less impressive.

Duplication

We looked at the main topics covered by all the guidance documents. The two biggest categories were "general" (ie general guidance on involving patients and public) and "research" (how to involve patients in research). These two categories had an exact match in terms of quantity, with 127 documents in each.

So someone with a general interest in PPI could read one document per week for two years and still not be finished. The same goes for research.

Other categories are, perhaps, more manageable. These include:

The purpose of engagement – for example, PPI in commissioning (39 documents) and in quality improvement (29 documents).

PPI processes, such as ensuring equality and diversity (40 documents), financial matters (23), governance (6) and impact (9).

Specific areas of healthcare, such as primary care (39 documents), mental health (15) and digital healthcare (18).

Specific groups and communities, such as families and carers (47 documents) and young people (28).

Equity

Debates on PPI recognise that engagement is not necessarily inclusive. Common terms are "hard to reach", "seldom heard" and "underserved".

So we might expect a particular emphasis in the guidance on ensuring equity, or fairness, in involvement. Here, though, the guidance seems thin. In terms of toolkits dealing with specific involvement issues for specific named groups, we found:

4 for Black and minority ethnic communities. 3 are generic to "BAME" and one is for the South Asian community

4 for LGBT patients and service users.

4 for people with physical disabilities.

2 for Gypsy, Roma and Traveller communities.

1 for people with learning disabilities.

1 for migrants.

When compared with the 127 documents offering generalised guidance on patient and public involvement, this does not amount to much.

5. Implications

For this attempt on the mountain of PPI guidance, our searches were exclusively within the Patient Experience Library[9]. The Library only collects open access literature, so it is possible that further guidance lies behind paywalls put up by journals and other research databases. So we might not have found all the guidance on PPI, but we are confident that we have found nearly everything.

Important learning points are as follows:

1. The guidance is now in plain sight.

Users of PPI guidance: It is now far easier to get the guidance you need. Use our open access evidence map to see all the toolkits referred to in this report, and find the one that will work best for you.

2. No one has to start from a blank sheet.

Prospective funders and writers of PPI toolkits: Look before you leap. Don't waste time and money adding to the areas of saturation. Instead, fill the gaps.

3. Loss of organisational memory is not inevitable.

National Institute for Health Research and NHS England Library and Knowledge Services: PPI guidance tends to be poorly catalogued and ephemeral. Much would have been lost were we not preserving it in the Patient Experience Library. Work with us to prevent future losses and build organisational memory.

4. We can end inequities in the guidance.

NHS England Health Inequalities Team: We can now see where guidance on involvement is poor at addressing the needs of seldom heard communities. Work with us to end inequity in healthcare by exposing the inequities in PPI guidance.

5. The work isn't finished

National Institute for Health Research and NHS England Library and Knowledge Services: In the few months since we completed our analysis, a further 22 PPI toolkits have been published. The flow is not going to stop. Work with us to keep our evidence map updated, and to understand where research funding can be better used in future.

6. Finally...

This report is part of a wider evidence mapping project for patient experience and engagement.

While medical research has rigorous prioritisation processes, evidence gathering on patient experience is, essentially, a free-for-all. One consequence is extensive duplication and waste. Another is big gaps in the evidence base. These are very often in relation to so-called "hard to reach" communities – the very people whose voices really need to be heard.

With funding from the Health Foundation's Q Community, we have undertaken the first ever exercise in mapping key areas of the evidence base on patient experience. Our results are being disseminated via a series of reports like this one, and through a set of interactive online evidence maps.

We are laying the foundations for better research prioritisation in patient experience – to steer time and money more effectively, and to help the NHS ensure that its promises of patient-centred care are soundly evidence-based.

Our evidence maps can help research funders to see how to get better value for money, help researchers to see how to avoid time-wasting and duplication, and help patient advocates to see who is – and is not – getting heard in patient experience evidence-gathering.

If you'd like to find out more about the project, or if you want to partner with us to produce more maps, please get in touch: info@patientlibrary.net

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Endnotes

1. https://www.scie.org.uk/co-production/what-how

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3. Baines R, Regan de Bere S. 2017. Optimizing patient and public involvement (PPI): Identifying its "essential" and "desirable" principles using a systematic review and modified Delphi methodology. Health Expect.

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5. Matthews, R. et al., 2019. How helpful are Patient and Public Involvement strategic documents – Results of a framework analysis using 4Pi National Involvement Standards. Research Involvement and Engagement. 2019 5:31.

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7. Greenhalgh T, Hinton L, Finlay T, et al. 2019. Frameworks for supporting patient and public involvement in research: Systematic review and codesign pilot. Health Expect.

8. Greenhalgh T, Hinton L, Finlay T, et al. 2019. Frameworks for supporting patient and public involvement in research: Systematic review and codesign pilot. Health Expect.

9. www.patientlibrary.net

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