Jungles, deserts and a mountain

Miles Sibley, Patient Experience Library

An NHS aiming to be both patient-centred and evidence-based needs a coherent evidence base for patient experience.

Medical research databases are in daily use across the NHS. But historically there has been no equivalent for patient experience evidence. So we built the Patient Experience Library to plug that gap.

We have spent the last few years cataloguing tens of thousands of documents on patient experience and engagement. In doing so, we have noticed a lot of duplication. There are, for example, hundreds of reports on people's experiences of trying to get a GP appointment. And they all say much the same thing.

We also noticed gaps in the evidence base. It is hard to find studies on topics such as people's understanding of advance care planning, or experiences of pelvic mesh, or the intersection between religious faith and experiences in healthcare.

Why, we wondered, does the evidence on patient experience seem so patchy? How, exactly, does the variability manifest itself? And (in an NHS that says it wants to tackle health inequalities) who gets heard, and who doesn't?

At the start of 2023, we decided to go looking for answers.

A voyage of exploration

We sampled five different parts of the patient experience evidence base:

- Patient experience in digital healthcare
- People's experiences of the Covid pandemic
- Experiences in urgent and emergency care
- The healthcare experiences of homeless people
- Experiences of people with rare disease

We headed out into each of these areas to see what we could see. Using a variety of search terms, we collected hundreds of reports on each topic, and then applied thematic analysis to help us make sense of the overall shape of each part of the evidence base.

What we found confirmed our worst fears.

Jungles

With every single sample of the evidence base, we found areas that were densely packed with repeat studies. This was not so much duplication, as saturation.

"Access to services" in particular is a topic that seems to get investigated over and over again, year after year. Funders are spending money, researchers are spending time and patients are expending goodwill for no good reason that we could see. Their efforts are simply adding to the pile of reports rather than to the sum of knowledge.

Deserts

Other parts of the evidence base were, to say the least, sparse.

In digital healthcare, we found very little on people's experiences of the NHS app, or experiences with electronic health records, or attitudes to artificial intelligence in healthcare.

In the literature on Covid, just 6% of the reports we found had a specific focus on health inequalities – when we know that the poorest communities were hit hardest by the pandemic.

A mere 2% were primarily about the pandemic experiences of people who are clinically vulnerable.

On the healthcare experiences of people who are homeless, we found just two reports on experience of food insecurity, and one on experience of hygiene poverty. And yet these are fundamental determinants of health in the homeless population.

Toolkit Mountain

As a bonus extra we took a sixth sample of the evidence base, looking at guidance notes, frameworks and toolkits for patient and public involvement. The quantity of published work is staggering: we found 536 PPI toolkits.

The problem is not with the quality: most of the guidance is well-written. But there is a mountainous quantity of it, and a great deal of it is both generic and repetitive. Guidance on engagement with "hard to reach" communities is largely noticeable by its absence.

Why this matters

There is a lot of talk in healthcare about health inequalities.

If we want to understand health inequalities, we have to hear from the people who experience them. But our evidence mapping indicates that health inequalities are perpetuated – at least in part – because those same inequalities are built into the way that patient experience evidence gathering is being done.

This is not a criticism of researchers. It is common to the point of cliché to hear that underserved communities are not actually hard to reach – it's just that researchers aren't trying hard enough. But that ignores the context in which researchers operate.

In medical research, there are clear prioritisation processes. Research funders, broadly speaking, know what they know, and they steer researchers away from duplication and waste. They also know what they don't know – so they can point researchers towards filling the gaps.

Patient experience work is different because no-one – until now – has mapped the evidence base to find out what we know and what we don't know.

So even when researchers are willing to make the effort to get to so-called "hard to reach" communities, they have trouble seeing who has already been spoken to and who hasn't. They might struggle to see what topics have already been covered, and where the gaps are. And unlike medical researchers, they don't get a steer on where to go next.

What now?

Our evidence mapping can put an end to what is, essentially, a free-for-all in patient experience research.

We have created a foundation for prioritisation processes of the kind that are routinely used in medical research and we have laid the basis for tackling inequalities in health by tackling inequalities in evidence-gathering.

So we are now looking for partners and collaborators to help take this work to the next level. To a point where researchers can stop wasting time. Where research funders can stop wasting money. And where the so-called "seldom heard" can come out of the shadows, and their presence or absence in the patient experience evidence base can become fully visible.

Do you want to partner with us? Please get in touch: info@patientlibrary.net