

# Every story matters

How people lived through the Covid pandemic, and what we know (and don't know) about their experiences.

**Patient Experience Library**



# 1. Prologue

“Every Story Matters” says the UK Covid-19 Inquiry. It is good to see people’s pandemic experiences being taken seriously as a source of learning and reflection.<sup>1</sup>

This, however, was not the case during the crisis phase of the pandemic. Vital intelligence gathering mechanisms such as national patient surveys were paused, scaled down, or cancelled altogether.

Happily, many organisations outside the NHS took it upon themselves to record people’s experiences and testimony. And we, the Patient Experience Library, decided to collate and preserve the evidence.

Nearly three years on from the declaration of the first UK lockdown, we find ourselves in possession of a unique archive. So we have combed through it to try to understand whose experiences were recorded, and which aspects of life under Covid have been documented.

We found a research landscape in which some topics have been covered extensively while others remain virtually untouched. Equally, some communities come through loud and clear while others are almost voiceless.

We look at the implications for national NHS bodies and for research funders, and suggest ways to get better value and better learning. And if you want to explore the evidence base for yourself, you can skip straight to our [interactive map](#) to see what it looks like.



# 2. Backstory

## Consequences

The consequences of the Covid pandemic have been profound. In the UK, nearly a quarter of a million people have died<sup>2</sup>, leaving even greater numbers dealing with bereavement and grief.

Up to 2 million people continue to live with Long Covid<sup>3</sup>, now recognised by the NHS as a long term condition<sup>4</sup>. Health and care services came under huge pressure during the crisis phase of the pandemic, and are now dealing with their own long term effects, particularly in terms of backlogs for treatments.

But Covid is not just a medical catastrophe. There have also been wide-ranging social consequences.

Lockdowns exacerbated loneliness and social isolation. Vaccines saved countless lives but also generated fear and mistrust. Visiting bans in care homes were meant to control infection, but forced families apart at times when they most needed to be together.

Understanding experiences like these is a vital part of learning lessons from the recent pandemic, and preparing for the next one.

## Every story doesn't matter

The UK Covid-19 Inquiry says that every story matters. But during the crisis phase of the pandemic, NHS evidence gathering on patient experience was deliberately halted.

The Maternity Survey was cancelled<sup>5</sup>, and the Cancer Patient Experience Survey was run on a much reduced scale<sup>6</sup>. Friends and Family Test national data collection was suspended<sup>7</sup>, as was national collection of complaints data<sup>8</sup>.

The NHS describes itself as both “patient-centred” and “evidence-based”. But just as patients and public were feeling the full force of the pandemic, NHS senior managers decided that systematic collection of their stories would not be necessary.

## Rapid response

Luckily, other (largely non-NHS) organisations realised the importance of tracking people's experiences through the pandemic. Health charities, patient voice organisations, policy think tanks and academic institutions all gathered evidence – often through the rapid and creative development of new forms of online engagement.

We too (the Patient Experience Library) realised that this was a unique opportunity to learn from an extraordinary episode in the life of the nation. So as the evidence was published, we worked as fast as we could to collect, catalogue and preserve it.

Now, with the crisis phase of the pandemic over, we have taken time to sift through our collection, and to try to understand the overall shape of this entirely new evidence base.



# 3. Every storyline matters

Many thousands of stories were gathered from individuals and communities during the pandemic. These can be woven together into storylines – common narratives of Covid experience, from which we can draw insight and learning.

But what are those storylines? What evidence-gathering has been carried out, and by whom? What topics have been explored, and which sections of the community have been spoken to? Equally, which topics have not been covered, and which communities have not been heard from?

## The numbers

We started with a simple count of the number of studies and reports we had collected. We have 696 documents, of which 409 (59%) are from peer-reviewed journals. The remaining 41% are mostly from local Healthwatch (120) and from charities and policy bodies (137). There are 30 from government sources.

Unsurprisingly, the years 2020 and 2021 were when most of the literature was published. There were 281 reports in 2020, rising to 339 in 2021. By 2022, the number had dropped to 76.

## Saturation

The strongest area of the evidence base is in studies examining people's access to, and experience of, health services. This makes up over one third (38%) of the topics covered.

The crisis period of the pandemic was of course the moment at which access to services changed beyond all recognition. Elective procedures were delayed, primary care appointments shifted to phone calls and online, and A&E attendance dropped dramatically. So it is understandable that researchers would rush to see how people's access and experience were affected. At the same time, it seems likely that there is a certain amount of duplication.

The second biggest topic area is "health and wellbeing during the pandemic". These tend to be somewhat generic accounts, in which study participants talk about anything from lockdown loneliness to mask-wearing, to anxiety and ability to cope.

## Gaps

To truly learn from public experience in the pandemic, we need to get beyond the low hanging fruit of service access and general wellbeing. We need a forensic examination of the experiences of people who were always more likely to be hit hardest by a widespread viral infection. Here, however, the evidence base seems thin.

“Health inequalities” accounts for only 6% of the topics covered within the reports that we found. NHS England recognises that “COVID-19 has shone a harsh light on some of the health and wider inequalities that persist in our society”<sup>9</sup>. So we might ask why it did not do more to encourage evidence gathering in this area.

Vaccines is another important topic. Here, a stunning medical achievement (rapid development of brand new medicines) was met, in some communities, by fear and resistance. But just 5.5% of the topics covered within the evidence base relate to public views on Covid vaccines.

Even more surprising is the quantity of evidence relating to the pandemic experiences of clinically vulnerable people. These people perhaps needed to be heard from most of all. But their experiences make up just 2.5% of the topics covered in the 696 reports we unearthed.



# 4. Implications

For this exercise in mapping the evidence base on patient experience of the Covid pandemic, our searches were exclusively within the Patient Experience Library<sup>10</sup>. The Library only collects open access literature, so it is possible that further evidence lies behind paywalls put up by journals and other research databases. Even so, there are some useful learning points:

## 1. A unique archive on patient and public experience during the pandemic is now freely available.

RESEARCHERS, POLICYMAKERS AND CAMPAIGNERS: Use our open access [evidence map](#) to see how we have visualised the evidence base, and to get access to the source reports.

## 2. The evidence base continues to grow.

The crisis period of the pandemic is over, but we continue to live with the consequences. And to learn from the pandemic we need more than just medical science. New research is emerging on topics such as people's experiences of Long Covid. Campaigners continue to battle for the rights of family members to visit loved ones in care homes and hospitals.

NHS ENGLAND: Work with us to continue the task of cataloguing people's Covid experiences so that services can learn how to be both person-centred and evidence-based.

## 3. We now have the basis for a more strategic and systematic approach to developing the evidence base.

We can now see the areas of saturation as well as the gaps in the evidence base on people's experiences of the pandemic.

NATIONAL INSTITUTE FOR HEALTH AND CARE RESEARCH AND NHS ENGLAND HEALTH INEQUALITIES TEAM: Use our findings as a basis for steering further research away from duplication and towards lesser heard communities.

# 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.

For more on the project, visit the evidence maps page on our [website](#). And if you want to partner with us to produce more maps, please get in touch: [info@patientlibrary.net](mailto:info@patientlibrary.net)



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## Endnotes

- 1 <https://covid19.public-inquiry.uk/every-story-matters/>
- 2 <https://coronavirus.data.gov.uk/details/deaths>
- 3 NHS England, Ipsos 2023. Long COVID patient experience research – Summary report. Page 11.
- 4 <https://www.nhs.uk/conditions/covid-19/long-term-effects-of-covid-19-long-covid/>
- 5 [https://content.govdelivery.com/bulletins/gd/UKCQC-28fa14e?wgt\\_ref=UKCQC\\_WIDGET\\_5](https://content.govdelivery.com/bulletins/gd/UKCQC-28fa14e?wgt_ref=UKCQC_WIDGET_5)
- 6 <https://www.ncpes.co.uk/2020-trust-results/>
- 7 <https://www.england.nhs.uk/fft/friends-and-family-test-development-project-2018-19/faqs/#when-will-fft-data-submission-resume>
- 8 <https://www.pulsetoday.co.uk/news/workload/nhs-digital-cancels-annual-collection-of-gp-complaints-data/>
- 9 <https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/>
- 10 [www.patientlibrary.net](http://www.patientlibrary.net)

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p4 Document mountain: WeStudio/Shutterstock p6-Missing pages: source - madisonamps.org

