

Patient experience: Mapping the evidence

Miles Sibley and Rebecca Baines



**Patient
Experience
Library**



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1. A question of value

The NHS constitution says that “The patient will be at the heart of everything the NHS does”¹. Alongside this, the NHS Long Term Plan promises that “People will get more control over their own health and more personalised care when they need it”². To fulfil these promises, the NHS needs to understand people’s experiences in healthcare.

With an ageing population, we need insight into how people live with long term health conditions. In a society characterised by health inequality, we need to know why some people find it harder to access the services they need. And for all patients, we need to understand what aspects of service quality matter most to them.

A mass of evidence-gathering seeks answers to these questions via surveys, focus groups, consultation exercises, patient voice networks, academic studies and more. The combined costs run to tens of millions of pounds every year^{3 4}.

This raises an important question: how can we know whether all this time and money is being well spent?

Unfortunately, it is hard to assess the value of patient experience research. That is because no-one has strategic oversight of the evidence-gathering effort.

In medicine, this would be considered unacceptable. Medical research has well established processes for research prioritisation, co-ordinated by bodies such as the National Institute for Health Research and the National Institute for Health and Care Excellence⁵.

In patient experience research however, there is no commonly agreed prioritisation process. This leads to problems as follows:

1.1 Unknown knowns

Guidance from NHS England says “There is a great deal of information being collected already that can be used before procuring something new or that can be used to ensure any new research is based on what we already know”⁶.

Unfortunately, this statement ignores the fact that most of the historic evidence on patient experience has been disposed of.

1 The NHS Constitution, 2015. Page 2.

2 NHS Long Term Plan, January 2019, p24.

3 Over half a million pounds per survey per year for each of the national patient surveys. Flott K, Darzi A, Gancarczyk S, Mayer E Improving the Usefulness and Use of Patient Survey Programs: National Health Service Interview Study J Med Internet Res 2018;20(4):e141

4 Healthwatch network funded at £25.5 million per year. Healthwatch England, 2020. State of support. Funding for local Healthwatch 2019/20. Page 3.

5 <https://www.nice.org.uk/about/what-we-do/science-policy-research/research-funders>

6 NHS England, 2016. Bite-size Guide to patient insight: Insight - what is already available?



Government has ploughed long-term investment into patient voice initiatives, starting with the establishment of Community Health Councils (CHCs) in the 1970s. Those were succeeded by Patient and Public Involvement Forums (PPIFs), then by Local Involvement Networks (LINKs), prior to the establishment of the current iteration, Healthwatch.

CHCS, PPIFs and LINKs all gathered large volumes of evidence on patient experience, but none of it was properly archived. So as each initiative shut down, its entire body of knowledge went with it.

NHS England urges researchers to make good use of time and money by ensuring that new research is based on what we already know. But without an archive, that is largely impossible.

1.2 The research free-for-all

There is some degree of co-ordination between some of the organisations responsible for gathering evidence on patient experience. For example, the Care Quality Commission and NHS England ensure that their respective patient surveys cover different services. Beyond that, there is little or no control.

Providers, commissioners, health charities, patient voice networks and academic institutions are all free to set their own patient experience research priorities without reference to one another or to any system-level steer on where the research effort might best be applied.

The consequences are visible in the daily cataloguing of reports collected for the Patient Experience Library. Some parts of the evidence base (for example on people's experiences of getting GP appointments) are saturated, with studies that add more to the pile of reports than to the sum of knowledge. Other parts of the evidence base (for example around areas of health inequality) remain persistently thin.

There is no system level means of directing time and money to where it can best be used.

1.3 Off the radar

The patient experience evidence base grows rapidly. Alongside the relatively steady pace of peer-reviewed academic publishing is a high volume of output from charities, campaign groups and think tanks, working to shorter timescales and more pressing deadlines. Thousands of papers, studies and reports are published every year, and it can be genuinely difficult to keep up.

The problem is compounded by judgements about what even counts as evidence.



Most of the patient experience literature comes from sources that formal researchers and policymakers would describe as “grey literature”. Strictly speaking, that means literature that is not peer-reviewed, not formally published (ie via professional journals) and not formally catalogued.

But grey literature is also seen in some quarters as second-best: variable in quality and potentially unreliable. It goes uncollected by professional research databases, and remains off the radar of the healthcare system as a whole. So its value can never be realised.

1.4 Hard to reach, hard to see

A recent study pointed to the problem of “researchers who don’t systematically and transparently refer to the totality of previous research when justifying and developing new research projects”. It advises that “health research should build systematically on previous research” and that “new research should be designed to answer both quality assured evidence gaps, as well as the needs and priorities from users and society”⁷.

We have shown above how a mixture of poor archiving, limited co-ordination and attitudes towards grey literature make it difficult, in patient experience work, for researchers to “build systematically on previous research”, and to spot “quality assured evidence gaps”.

But the difficulty in spotting gaps also makes it difficult to address the question of “needs and priorities from users and society”. To address those needs, we need to know who is – and is not – being heard in patient experience research.

This has been understood for some time. In debates on “patient and public involvement” there is always the question of people and communities who are described as “hard to reach”. But the fact is that we do not really know, in any systematic way, the extent to which “hard to reach” communities are featured (or not) in the patient experience evidence base. They are, to all intents and purposes, invisible.

7 Ormstad et al. 2021. The Bridge Building Model: connecting evidence-based practice, evidence-based research, public involvement and needs led research. *Res Involv Engagem* (2021) 7:77 <https://doi.org/10.1186/s40900-021-00320-y>



2. Mapping patient experience

Against the background set out above, we considered how we might help health professionals, patient advocates and researchers to see what is in the existing evidence base before embarking on new studies.

Ideally, we would be able to help 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 how and whether different sections of society are represented in patient experience evidence-gathering.

Ultimately, we wondered whether we could lay the foundations for better research prioritisation in patient experience - steering time and money more effectively, and helping the NHS to ensure that its promises of person-centred care are soundly evidence-based.

Our aim was to find a way to understand and visualise the scale and nature of the UK patient experience evidence base.

We decided to sample the evidence base across two key themes:

Patient and public experience of Covid-19

Digital healthcare from the point of view of patients

For each theme, our objectives were as follows:

- Produce a quantitative analysis, covering total number of documents, plus distribution by:
 - Year
 - Type (Government, Healthwatch, other)
 - Place, where relevant (e.g. town, city, county)
 - Population group (age, gender, ethnicity)
 - Topics covered (e.g. under Covid, this could include experiences of lockdown, attitudes towards vaccines etc)
- Create visualisations to show the analysis in ways that could be explored and interrogated.
- Explore the possibility that the analyses could be replicated and automated for future use on other topics within the evidence base.

Our method is set out in full in Appendices 1-3.



3. Findings

We found that it is indeed possible to map the UK evidence base on patient experience.

Our searches returned 562 documents relevant to “Patient and public experience of Covid-19” and 126 relevant to “Digital healthcare from the point of view of patients”. Our coding framework enabled us to identify and quantify main themes and sub-themes within these overall topics, and by applying bespoke analytical processes, we could then generate queries to feed into interactive evidence maps.

The maps enable users to interrogate the evidence by year, main topics, place and population group. Screenshots of the evidence maps can be seen in Appendices 4 and 5, and an online demonstration can be seen [here](#).

The maps are based on quantitative analysis – but they also reveal valuable insights into the qualitative nature of the evidence base. Some examples are as follows:

3.1 Type

It can be seen that in both themes (Covid and digital), the biggest single source of reporting is the Healthwatch network. This might have something to do with the size of the network, which comprises around 150 local Healthwatch across the whole of England. But it might also say something about the way that local Healthwatches are rooted in local communities – drawing staff and volunteers from those communities, and spending years in building trusted relationships.

The fact that Healthwatch is the biggest single source of evidence is important. Their reports would generally be seen by academics and policymakers as “grey literature” – defined as literature that is not peer-reviewed, not formally published (ie via professional journals) and not formally catalogued.

Because of these qualities, grey literature can be invisible to formal researchers, or even if visible, can be seen as variable in quality and potentially unreliable. Our findings demonstrate that this is nevertheless an extensive source whose outputs should perhaps be routinely examined and compared with outputs from more formal sources.

3.2 Main topics

It is striking that for both Covid and digital, getting on for half of all reports (over 40%) are about people’s experiences of service access. This is undoubtedly a compelling issue at a time of growing backlogs in elective care and rapid development of remote appointments and consultations. But it contrasts strongly with just 7% of reporting on health inequalities (within the Covid theme) and 8% on digital exclusion (within the Digital theme). Within



the Covid theme, a mere 1% of reports look at the experiences of people who are clinically vulnerable.

The “main topics” mapping achieves a crucial goal of our study: to expose areas of saturation in the evidence base, and reveal gaps. If bodies such as NHS England or NIHR were to start thinking about a more strategic approach to patient experience evidence-gathering, they could perhaps consider whether we need further reports on service access, or whether time and money might be better spent with people whose experiences are visibly absent from the literature.

3.3 Population groups

Our mapping of population groups shows an uneven distribution of evidence across age, sex and ethnicity. Among the Covid reports that focus specifically on age, young people are well represented, with 32 reports, against just 3 looking at the experiences of older people.

In Covid reports looking specifically at experience of minority ethnic groups, the generic “BAME” is the biggest single category. (NB: Category descriptors – “African”, “BAME” etc – are taken from the reports themselves.) BAME is, moreover, the biggest category out of a very small group, with just 18 reports from our overall total of 562 looking at the specific experiences of minority ethnic groups.

In the literature on experiences of digital healthcare, younger people are again proportionately best represented. There is also a focus on some health condition groups, but we were unable to find any reports looking specifically at the experiences of minority ethnic groups. As with the “main topics” findings, this should act as a prompt to researchers and their funders to think more carefully about how and where they direct future research.

3.4 Location maps

Our visualisations include location maps which reveal how patient experience is being explored and documented in different parts of the country. Here too, we found unevenness, with, for example, 11 reports from Oxfordshire on experience of Covid within the county, as opposed to just one in Norfolk.

This will prove useful to researchers and policymakers wanting to see, for example, what work has been undertaken in rural areas, or within a particular Integrated Care System area. It might also be possible to link the maps to other indicators such as the Index of Multiple Deprivation, to see what research has been carried out in areas of relative wealth or poverty.



4. Conclusion and next steps

The results of our study are a first in the world of patient experience work, and represent a major breakthrough.

Our visualisations show that it is possible to bring the evidence base into view. We can show both the scale of it (quantitative mapping) and the nature of it (qualitative mapping). This could be a very powerful tool for researchers, research funders and patient advocates.

Our work has implications for value for money in patient experience research. It also offers the possibility of tackling health inequalities by bringing some sections of society more visibly into the evidence base.

A key objective (section 2 above) was to “Explore the possibility that the analyses could be replicated and automated for future use on other topics within the evidence base”.

Since our approach works for patient experience of Covid, and of digital healthcare, we are confident that it will work for other areas of the patient experience evidence base as well. So the task of replication seems eminently feasible. We could envisage mapping the evidence base by:

- Condition: For example, patient experience of autism, or Parkinson’s, or cancer.
- Service type: For example, patient experience of maternity services, taking in labour and birth, perinatal mental health, antenatal education etc.
- Socioeconomic group: For example, end of life experiences for different faiths, the healthcare experiences of homeless people etc.

As far as automation is concerned, we have already made significant strides. Functionality within the Patient Experience Library enables powerful search across whatever part of the evidence base is being mapped, with automatic sorting of search results by author/publisher, title, date and relevance. Further automation would enable us to pre-sort for matters such as:

- Type of literature: e.g. peer-reviewed or not.
- Location of studies: to rapidly populate the location maps (see examples in Appendices 3 and 4).
- Linking locations to the Index of Multiple Deprivation (to explore aspects of health inequality).

Finally, our [online demonstration](#) allows viewers to see what the maps can do, but does not give them direct access. Added functionality within the Patient Experience Library would enable users to manipulate and interrogate the maps for themselves, democratising the knowledge contained within them.



For too long, patient experience evidence has been a poor relation to medical research. Baroness Cumberlege's First Do No Harm report has said that patient experience "must no longer be considered anecdotal, and weighted least in the hierarchy of evidence-based medicine"⁸.

We hope that our mapping techniques will be seen as an important step towards responding to Cumberlege's call, and as a valuable way to help the NHS to ensure that its promises of person-centred care are soundly evidence-based.

DECLARATIONS

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8 First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020.



Appendix 1: Method

A1.1 Research Question

Our research question was “How can we quantify the scale and nature of the evidence base on patient experiences of Covid-19 and digital healthcare, and how might this be visualised?”

A1.2 Search strategy

A.2.1 SEARCH TERMS

Two sets of searches were conducted in the Patient Experience Library database using the following terms (listed alphabetically):

Covid theme:

Coronavirus

Covid

Elective

Lockdown

Pandemic

Shielding

Vaccine

Visiting

Waiting

Digital healthcare theme:

Data

Digital

Online

Remote

Telehealth

Telecare

Virtual

Zoom

A1.2.2 EXCLUSIONS

Place: For the Covid theme, evidence was taken only from English sources. This was a pragmatic decision based on the volume of reports, against the short timescale and limited budget for this project. For the digital theme, there were no exclusions - evidence was accepted from across the UK and overseas.



Time period: There were, for the most part, no exclusions, as the Covid literature is recent, and most of the literature on digital healthcare is less than ten years old. The exceptions, within the Covid theme, were for “elective”, “vaccine”, “visiting” and “waiting”. For these, searches were limited to January 2020 onwards, to be sure of getting search results relevant to the Covid period. The search was conducted in August 2021, and included documents up to and including that month.

Sources: Evidence was not drawn from documents that are held behind journal paywalls, or other literature that would normally be for sale from booksellers. Our evidence was from open access sources (government, patient voice, charity, academic etc).

Relevance: Search results were filtered for relevance, to include only those documents that explored exclusively, or mainly, public experience of Covid and digital healthcare.

A1.3 Evidence base

The search was conducted exclusively within the Patient Experience Library, which acts as the national evidence base for literature on patient experience and involvement, and has developed specialist cataloguing, search functionality, and analytics.

A1.4 Coding and analysis

The search returned 562 documents relevant to Covid, and 126 relevant to digital healthcare. These were read manually, and sorted into topics using coding frameworks as shown in Appendices 2 and 3. Development of the frameworks was both inductive and deductive - starting with elements that we expected to be revealed in the literature, then adjusting and/or adding as we worked through the process.

A1.5 Limitations

This project was carried out as a small scale proof of concept study, over a tight six-month time period.

Because of this, our samples are necessarily small. One example is that the mapping includes reports published during 2021 - but only up to August, when we carried out the searches. For the Covid map, we found 562 reports, but anticipate that by the end of 2021, that figure might have been closer to 800.

The location maps are similar - within our time and capacity, we were able to map reports by district and county. With more time, we could map the evidence to individual towns and cities.

Given these limitations, we suggest that this study be taken as a proof of concept, rather than a comprehensive analysis.



Appendix 2: Coding and analysis – Covid

The search returned 562 documents relevant to Covid. These were read manually, and sorted into topics using a coding framework as shown below. Development of the framework was both inductive and deductive - starting with components that we expected to be revealed in the literature, then adjusting and/or adding as we worked through the process.

Main topics	Subtopics
Delayed/cancelled treatment and care	Dental Care
	GP Appointments
	Patient Transport Services
	Hospital Services
	Mental Health Services
	Social Care
	Cancer Services
	Stroke Rehab services
	Neurological Services
	Rheumatology outpatient services
Cardiovascular care	
Service access and experience	Health
	Health and social care
	Home COVID testing
	Social care
	Mental health
	Primary care
	Hospital care and discharge
	Urgent and emergency care
	Giving Blood
	Pharmacy
	Dental
	Eye Care
	Weight services
	Maternity
	Out of hours
	Care home
	Experience of rapid testing service
	Remote consultations
	Prisons
	Attitudes towards and experiences of the NHS during Covid-19
	Patient Transport Services
	Community support services
	Cancer treatment during COVID-19
Dementia Care	
End of life care during Covid-19	



Main topics	Subtopics
Vaccines	Vaccine experiences Vaccine hesitancy Vaccine information Vaccine preparedness Vaccine priority Unpaid carers
Public Health Health Inequalities	Government handling of the Pandemic Access to testing NHS Staffing levels Healthcare access to PPE Guideline Communication Digital Access Co-morbidities Non English speakers SEND Homeless Disabilities LGBTQ+ Rural health services
Online information and advice	Peer Support Primary care communication Social Care advice and communication Government shielding advice Carers
Research	NHS Resource Allocation during COVID Inequities in mental health research exacerbated by covid Services Audit COVID mortality statistics Social Care during COVID Public involvement in research COVID Rehab advice Long-COVID Experiences Digital interventions Clinical research
Future planning	Building back elective care Policy Making GP Services Consequences of COVID response NHS Staffing Charity financial future Long Covid Treatment



Main topics	Subtopics
Digital Transformation	Covid-19 app use and adoption
	Covid19 innovation and transformation
Social care	How social care should be paid for
	Impact of COVID on Charities
	Impact of COVID on Carers
	Leadership
	Carehome access to PPE
	Homelessness during COVID-19
	Young carers
	Unpaid Carers
	Communication
	Adult social care
Clinically vulnerable	Care home residents
	Underlying health conditions
	Long term health conditions
Health and wellbeing during pandemic	Impact of Covid-19 on mental health
	Impact of Covid-19 on long term conditions
	Domestic Violence/Abuse
	Impact of COVID-19 on DNR
	Maternity
	Obesity
	Relationships
	Education
	Financial support
	Food



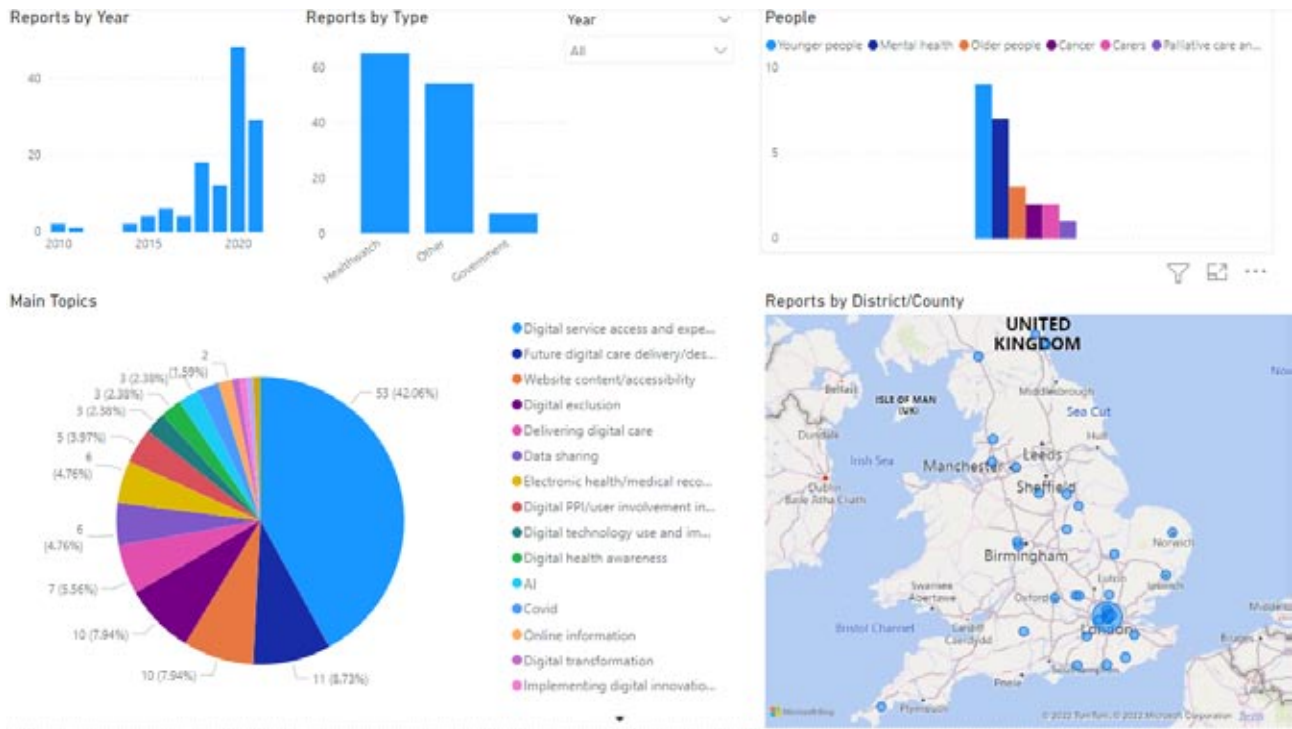
Appendix 3: Coding and analysis – Digital healthcare

The search returned 126 documents relevant to Covid. These were read manually, and sorted into topics using a coding framework as shown below. Development of the framework was both inductive and deductive – starting with components that we expected to be revealed in the literature, then adjusting and/or adding as we worked through the process.

Main topics	Subtopics
Digital exclusion	Digital exclusion
	Digital inclusion
	Digital skills
Delivering digital care	Mental health
	virtual rounding
	Virtual family advisory board
	Building rapport
Digital transformation	Technology and the NHS estate
Future digital care delivery/design	Paediatric
	Primary care
	Large scale digital change
Digital service access and experience	Health
	Health and social care
	Mental health
	Primary care
	Inequalities in access/digital divide
	Online community forums
	Dental
	Remote consultations
	Pharmacy
	Cancer care
Implementing digital innovations	Digital health adoption
Covid	Impact of covid on technology use
	Covid19 technologies
	Covid-19 Digital recovery
AI	Heart and regulatory disease
Online information	Carers
Website content/accessibility	Website content/accessibility
	Pharmacy
	Dental
	Carehomes
	mental health
	Primary care
	Complaints
Digital PPI/user involvement in digital	Digital PPI/user involvement in digital
Digital PPI/user involvement in digital	Online patient participation groups

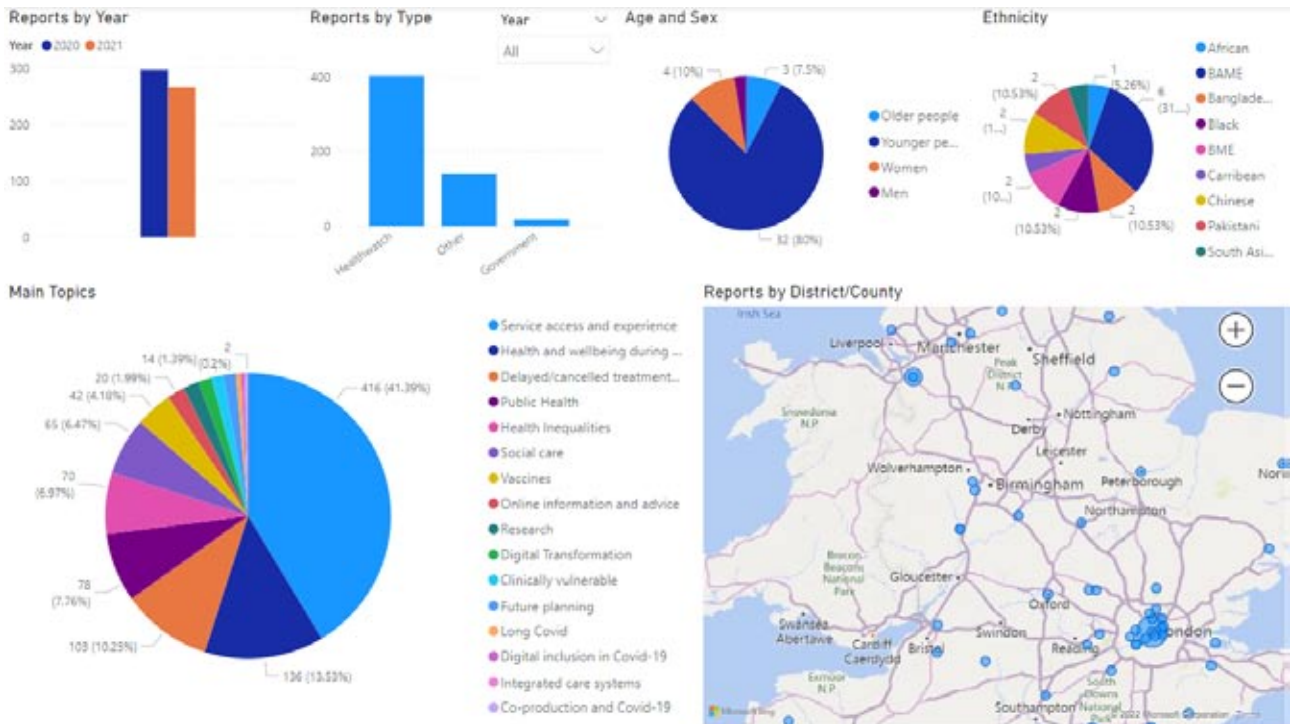


Appendix 4: Screenshot of interactive evidence map for patient and public experience of Covid-19





Appendix 5: Screenshot of interactive evidence map for Digital healthcare from the point of view of patients.



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