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There is no single truth about Covid-19

Miles Sibley, Director at the Patient Experience Library, explains why we need to look at qualitative data to really understand the impact of Covid-19 on people's lives.

We all know the importance of data for learning. In healthcare, good data can underpin policy making, clinical practice and the development of new drugs and treatments.

So it is good to see government bodies talking about [the power of data in a pandemic](#). The statement, published just as the lockdown was starting, announces a new initiative to collate data on the effects of the coronavirus. It says that "Without a single place to gather and analyse this data, decision-makers are unable to move as quickly as the response demands". And it sets out plans for a data platform that will help "national organisations responsible for coordinating the response... to make informed, effective decisions".

This is welcome news, and now, some months later, the [NHS COVID-19 Data Store](#) is fully up and running. It contains an impressive array of datasets - and we must hope that the data is reliable. After all, a notable feature of the Covid-19 crisis has been the release of [questionable statistics](#) on matters such as the quantities of personal protective equipment distributed, the scale and effectiveness of "test and trace", and infection and death rates.

One way to both check the validity of the numbers, and to dig deeper for greater insight, would be to include qualitative evidence in the Government's data collection, alongside the numerical data. That means talking with patients, carers and the wider public about their personal experiences of the pandemic. A "person-centred" healthcare system would surely want to do this. And yet on this matter, the Government is strangely silent. Its data collection efforts do not seem to extend into the realms of human experience.



There is no single truth about people's lived experience of the Covid-19 crisis.

Miles Sibley, Director at the Patient Experience Library

Why patient experience matters

The lack of focus on people's experience of Covid-19 seems odd because it became apparent very early on that Covid-19 affects different people in different ways. Older people seem to be more vulnerable, as do people from Black, Asian and minority ethnic communities, and people with some types of long-term health conditions. Some people have the disease but show no symptoms at all, while others die. Some get ill and recover quickly, while others report a "long Covid" with persistent and recurring symptoms.

The effects of Covid-19 are not just physical. Prolonged lockdown - particularly for people who are shielding - can lead to social isolation, increased anxiety and poorer mental health. And for people of working age, fears about reduced income and possible redundancies can also be stressful. [Recent research from Ipsos Mori](#) suggests that while men may be more vulnerable to the physical effects of the virus, women seem to be worse affected in terms of mental wellbeing.

There is more: patients without Covid-19 symptoms still need normal healthcare. But [the Independent has reported](#) that "infection precautions mean only half the normal number of operations a day can be carried out". It says that "hospital leaders warned the impact of [coronavirus](#) will mean longer waits for treatment... and a need to ration care". How will longer waits and rationing affect people's physical and mental health - and what might the consequences be for health inequalities?

A Government that wants national bodies to make "informed, effective decisions" needs to ensure that its data collection includes the patient voice. We need to understand people's experiences - in all their variety - of living with and through the pandemic. A response to Covid-19 that fails to include experiential evidence seems worryingly incomplete.

Plugging the gaps

The gaps in the data are compounded by a rapid abandonment of patient experience evidence gathering as the lockdown began. According to [this article in the BMJ](#), "This included stopping all work with patient participation group (PPGs); stopping the collection and reporting of patient experience data; delaying responses to complaints; and stopping any local gatherings of patient groups". The author goes on to make the point that "How quickly and easily this work was stopped raises questions about how it is really valued".

In the absence of governmental effort, non-governmental organisations have had to take the initiative in plugging the gaps. National Voices has been collecting first person accounts via their [Our Covid Voices](#) project. And the [Patient Experience Library](#) has been collating and cataloguing the growing literature on people's experiences through the Covid-19 crisis. A search in the library for "covid", "coronavirus" and "lockdown" reveals numerous reports on access to care, challenges for care home residents and visitors, the particular needs and concerns of BAME communities, the effects on people's mental well being and more. Initiatives like these can help to build a comprehensive evidence base for patient experience through the pandemic.

Next steps

The Government's [power of data in a pandemic article](#) says that the data store aims to "provide a single source of truth about the rapidly evolving situation". But there is no single truth about people's lived experience of the Covid-19 crisis. Men and women, Black and white, old and young experience it differently. Quantitative data can never provide a single source of truth - it can only provide a partial picture. And that is not a sound basis for "informed, effective decisions".

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As we settle into a "long Covid" at the national and societal level, we need more, and deeper understanding of how people's lives are affected. The NHS data store is undoubtedly doing a good job. But alongside it, we need a properly catalogued and freely accessible store of qualitative evidence - enabling us to check the stats against personal testimony. We need to preserve the evidence over time so that the healthcare system can start to build an organisational memory for what works and what doesn't - from the point of view of service users. And as the evidence base builds, we need to develop a strategic overview of its inherent strengths and weaknesses, so that research effort and funding can be steered away from duplication and waste, and towards building new knowledge where it is really needed.

The Patient Experience Library is committed to continuing its own efforts in this direction. It would be good to be doing so in collaboration with governmental organisations.