

Data sharing during this public health emergency

In these difficult and worrying times, colleagues in the NHS and the social care system are responding to coronavirus COVID-19 with great commitment and selflessness. It is inspiring and humbling to see the levels of devotion from our health and care staff, including all those working alongside clinicians to deliver other key roles on the frontline and behind the scenes.

As a former NHS doctor, I recognise their steadfast dedication to saving lives. And as a patient and service user, I share with my fellow citizens the admiration and gratitude for their bravery and professionalism. We are right to be proud of them.

To protect them, and all of us, the health and care system must now work together to manage the outbreak successfully: monitoring and responding to COVID-19 as effectively as possible. Data plays a vital role in this in so many ways.

From tracking the spread and transmission of the virus, to planning how best to manage resources, and, of course, in the provision of individuals' care – each of these elements is shored up by the power of data.

One of the many wonderful things about our NHS is the unrivalled dataset that it gifts us. As our universal health care system covers almost every person in the country, we have the potential to have consistent, coherent information about patients and the effectiveness of their treatment. And because the knowledge contained within this information is key to the management of the pandemic, it has never been more important to get the right information, to the right people, at the right time.

I have found it very reassuring to see that those with the knowledge, skills and power to make this happen are coming together very quickly to ensure that data is available to doctors, nurses, data scientists, service planners and researchers whenever they need it.

I have seen many examples of rapid action and problem solving at work. Such as [NHS Digital providing information](#) to help identify the most at-risk citizens very quickly, and NHSX providing [guidance to clinicians](#) on appropriate ways to communicate, share information and deliver care, which I endorsed.

Information sharing must be done differently to support the fight against COVID-19 and to protect citizens compared to ordinary times. Information may need to be shared more quickly and widely across organisations than normal, or different types of information may need to be collected and used.

We know from dialogue with the public, conducted by our organisation and others in the past, that there is strong support for the use of health and

care data where there is a clear public benefit. People are generally altruistic about the use of their data and want it to be used to help others as long as there are appropriate safeguards in place. I understand that doing things differently can usher in uncertainty about what is and isn't appropriate from a data sharing perspective; the worry may be that people will share too much or too little. So, we must make sure that we have the balance right to protect that admirable altruism.

What has become apparent is how well our information governance framework is able to flex in a time of public health emergency to serve as an enabler to the rapid sharing of information while maintaining proportionate safeguards.

The COVID-19 response has proven just how effective our confidentiality safeguards are, and how quickly laws and clauses supporting the sharing of confidential patient data in a time of crisis can be activated. This includes the formal notifications published by the [Department of Health and Social Care](#), which notifies healthcare organisations, GPs, local authorities and arm's length bodies about how they should share confidential patient information to support efforts against coronavirus. This is limited to Covid-19 purposes, for a time-limited period (initially to 30 September, with scope to extend) and requires organisations to keep records of all data processed.

The [National Data-Opt Out](#) has an exemption built in which means that it does not apply when there is an overriding public interest in the use of data, such as there is now. The GDPR has provisions to allow personal data to be used appropriately and lawfully at such a time. The [Information Commissioner has clearly announced](#) that data protection concerns should not stand in the way of appropriate information sharing; a statement which I fully endorsed.

With so much going on behind the scenes with people's data, it is important that patients and service users are fully informed about these changes. We must make efforts to tell citizens what's happening with their data; the need for transparency and good communication with patients still remains. Even in times such as these, protecting trust in confidential health and care matters. The guidance and notices issued to allow data sharing to combat the outbreak still contain appropriate safeguards: limiting the purposes for which data can be used, who can use it and the amount of time for this to occur. These are important protections that patients may be glad to hear about.

It is with gratitude that in the thick of everything I have still heard colleagues cite the importance of protecting confidentiality. Practical steps are also being taken to ensure that trust is not undermined. For example, my panel and I have been pleased this week to support NHSX with the drafting of a template privacy notice, which will be sent out to NHS organisations next week to support them to tell patients and service users about what might be different in the handling of their health and care data during the outbreak. It is heartening to note that even at this unprecedented crisis, trust and confidentiality still matter.

My panel and I will continue to monitor the response to COVID-19 and stand

ready to support our colleagues across health and care however we can. We send our gratitude to each and every individual involved in the response to the crisis and in bringing it to an end.