

# Exploring the barriers to information sharing for direct care

Today we have [published the findings and recommendations](#) from a survey we conducted about the perceived barriers to information sharing in support of people's individual care.

High quality health and care services depend upon effective communication between professionals, patients, service-users and carers across different organisations and at multiple points in a person's interaction with the system. However, we know that relevant information is often not available to health and care professionals or to the individual themselves. This can affect the quality of the care and health outcomes – professionals may be left without the information they need, and individuals are not empowered as they should be as partners in their own care.

We asked those working within health and care to help us better understand the impediments that are stopping the sharing of this essential information.

## **Why we carried out the survey**

The reticence to share information, even when it is in the best interests of a person's individual care, has long been matter of concern for the National Data Guardian.

[The Information Governance Review](#), which Dame Fiona Caldicott carried out in 2013, described a 'culture of anxiety' around data sharing and led her to add a 7th Caldicott Principle to the existing 6: The duty to share information can be as important as the duty to protect patient confidentiality.

But despite the 7th Caldicott Principle, the problem persists.

In early 2019, during a [consultation to seek views on her proposed work priorities](#), the NDG heard that more needed to be done to encourage better information sharing between health and care staff in support of people's care. Respondents supported the proposal that the NDG should work with others to ensure that information governance is embedded into professional training and development to better equip staff to share with confidence.

As a result, the NDG set 'Encouraging information sharing for individual care' as one of her three key priorities. The consultation also identified a call for the NDG to use her influence to improve patients' access to their own health and care records, and so she committed to work with the relevant bodies to explore the barriers to improving access.

This survey and its recommendations support both of these commitments.

## **A valuable snapshot of data sharing before the pandemic**

This survey was carried out before the COVID-19 pandemic struck. Since then, we've been pleased to support work to break down some of the barriers to information sharing at an accelerated pace. In response to the public health emergency, individuals and organisations have quickly rallied to make sure that information is in the hands of those who need it, when they need it, to support both the management of the outbreak and the care of those affected by it. This has not always happened perfectly, but it is a welcome change – including in mindset and attitude – towards better information sharing.

Of course, this has all taken place within exceptional circumstances and it raises a number of significant questions. What will data sharing look like when we return to 'normal'? What lessons have we learned that should inform future policies on data sharing? Which ways of working are helpful and should be permanently retained, and which stood down?

We believe that the snapshot that our survey gives of the world before COVID-19 is particularly valuable for answering these questions. It gives a clear view of the information sharing barriers that we must avoid reinstating. It underlines the importance of training for staff, so that they can share data well and with confidence. And it shows strong support for better access for individuals to their own health and care information.

### **What the survey findings tell us – key findings**

- The barriers to information sharing emerged as six themes: poor infrastructure, lack of integration and system complexity; anxiety about legal and regulatory complexity; concerns about breach of confidentiality; professional and organisational culture; lack of education, training and guidance; concerns about onward sharing of confidential information.
- The law around data protection and confidentiality is complex and many find existing guidance unclear or inaccessible. Ignorance, perceived complexity of regulations, fear of the law – particularly of GDPR – and concerns about breaching confidentiality, were frequently given as examples of why data is not shared to support direct care. Many find the distinction between direct and indirect care unclear and hard to apply.
- Data is often not flowing well across organisational and geographical boundaries. Concerns about data quality may also reinforce reluctance to share.
- Sector-wide guidance on information sharing, and accessible local training on the law and Caldicott Principles would help.
- There was strong support both for patients' access to information about their health and care and a presumption that patients should have such access. But technical, legal, organisational and workload barriers need to be addressed if patient access to information about their health and care is to become a system-wide reality.

### **The NDG's recommendations**

## **Recommendation 1**

Develop an education and training strategy to encourage information sharing for individual care that includes:

- Accessible and authoritative sector-wide guidance
- Clear, consistent, and accessible use of language
- Measures to promote a culture of safe sharing to support personal care
- Exemplars of good practice
- Consistency with new models of care and emerging technology challenges.

## **Recommendation 2**

Provide clarity about what falls within direct care and what does not. Any new guidance needs to use clear language and be consistent with a changing health and care landscape. To fill the gap until such time as this recommendation can be met in full, we have developed a draft [decision-support algorithm](#) which may help frontline health and care professionals. If validated and assured, such a decision-support tool could be incorporated into an app or clinical / care record system. Some colleagues who have road tested this decision support algorithm have given positive feedback.

## **Recommendation 3**

An approach should be developed to ensure patients, carers and service users can access important information about their health and care in ways that help them understand the content and context of that information.

## **Recommendation 4**

A better understanding should be developed of what specific data and information is required by the health and care system to meet the different demands of care provision, research and planning. This should be combined with an increased focus on data quality, structure, and access hierarchies. This would enable the relevant data (and only the relevant data) to be accessed by the appropriate teams and the appropriate points, without the issues that could be caused by the sharing of the entire patient record.

## **Next steps**

[Our report](#) has had positive reaction from the stakeholders who have read and reviewed it prior to publication. We have heard from clinicians that the findings resonate, and the recommendations are appropriate. The Health and Care Information Governance Panel, a group that has been convened by NHSX to lead on ensuring information governance guidance and policy is clear and simple, has reviewed and supported all of our recommendations. We look forward to working with partners to see how they can best be implemented.

But we'd like to hear what others think about the recommendations too. If you have any thoughts, please write to us at [ndgoffice@nhs.net](mailto:ndgoffice@nhs.net) so that these can be fed into work with partners to consider what should happen next on our recommendations.