

## The Health Foundation's response to the National Data Guardian's consultation on priorities.

*March 2019*

### Summary of our response

The Health Foundation welcomes the opportunity to comment on the National Data Guardian's consultation on the key priorities. The principles of safeguarding patient data are well-established and The Health Foundation believes that the National Data Guardian (NDG) will continue to play an important role to ensure these principles are applied. As potential innovative uses of data continue to emerge, The Health Foundation believes that the NDG can play an equally important role by providing a framework to ensure that patients' data can be shared where there is a potential benefit in doing so, while respecting the wishes of patients. We highlight the Seventh Caldicott Principle that can sometimes be overlooked. The NDG can emphasise this principle to ensure patients benefit from the adoption of new technologies and innovations using their data.

### About the Health Foundation

The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK. Our aim is a healthier population, supported by high quality health care that can be equitably accessed. We learn what works to make people's lives healthier and improve the health care system. From giving grants to those working at the front line to carrying out research and policy analysis, we shine a light on how to make successful change happen.

### Priority 1: Encouraging access and control: individuals and their health and care data

**Should giving people access and control of health and care data be one of the NDG's top priorities?**

The Health Foundation believes that giving patients access to their data means patients are brought into the data sharing process and increases understanding about how their data are used for purposes beyond their individual care. This increases transparency and awareness about the use of their data, and builds trust, which can encourage further use of data to benefit the quality of patients' care in the future. Without the use of patient data, valuable health service evaluation and research that benefits and improves the quality of patients' lives would not be possible.

These data need to be managed for the benefit of the NHS and its patients. A bigger conversation is needed with the public about data sharing, both to build public trust and also to empower individuals to contribute to decisions about how data about them are used.

We think that the public are still largely unaware of how their data are used beyond their care. Increasing awareness of how their data are used is important before their data are used to test new technologies. Increasing this awareness will help earn the trust of patients when their data are used to test innovative solutions in health care. There may well be lessons that can be adopted from other sectors, and we can advise the NDG on these. For example, the Open Data Institute is piloting the concept of a 'Data Trust'<sup>1</sup>, which is about developing models of control that aren't just technical but are also organisational in nature too.

When it comes to control over how patient data are used, we acknowledge that NHS Digital has provided a straightforward solution to enable patients to opt-out of their data being used beyond their direct care. This doesn't necessarily equate to having 'control' over what their data are used for if they don't register a general opt-out preference. Care should be taken about how control could be exercised by patients: data completeness is essential for robust analysis to be undertaken, so that service improvements that benefit the quality of care can be realised. We are fortunate that we have such rich data about secondary care provided by Hospital Episodes Statistics; our National Cancer Registry is world-class, enabling us to understand cancer better. Our ability to gather insights and support organisations to plan NHS services rely on complete data from administrative and survey sources.

This highlights the need for a conversation about what control is. Raising awareness of how patients' data are used, including the benefits of using these data, is the first step. Establishing preferences for how data are used is a more complex area to tackle. Furthermore, we need to demonstrate that control is a meaningful choice: evidence suggests that more available options for consent can reduce comprehension about data use.

**Are the outlined areas of NDG interest the right ones for the NDG? (Please tell us if there are other areas we should be looking at under this theme or if you think others are better placed to do this work)**

The Health Foundation believes the three areas of interest are the right ones for the NDG to focus on. In particular, the NDG has an important role in facilitating discussion and debate about transparency and control over data. However, views should be taken from multiple other organisations that have expertise and experience in this area. This includes data suppliers such as NHS Digital and Public Health England; but charities such as Cancer Research UK, Macmillan Cancer Support, and organisations such as Understanding Patient Data, UseMyData and MedConfidential, all hold views that can usefully inform this debate. While we welcome efforts to explore how patients can control data, we equally have to be

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<sup>1</sup> Open Data Institute. <https://theodi.org/article/defining-a-data-trust/>

mindful of the importance attached to collecting data in the first place, and the consequences if data are not collected.

Technologies (including but not limited to apps) developed outside the NHS could assist and the NDG should be open to allowing providers in this sphere to assist the NHS with this work.

### **What would you like to see the NDG do in this area?**

The Health Foundation would like the NDG to encourage key organisations who collect patient data, and provide access to these data to others (such as researchers), to develop ways that patients can easily understand how their data are being used for purposes beyond their immediate personal direct care. Additionally, we would like the NDG to facilitate a discussion about how patients can control and participate in data use.

At the very least, The Health Foundation encourages researchers and others who use patient data to have a dialogue with patients about how their data will be used. Understanding Patient Data is an initiative which makes available a number of resources to help researchers think about going about this.

### **Priority 2: Using patient data in innovation: a dialogue with the public** **Should use of patient data in innovation be one of the NDG's top priorities?**

New technologies are being developed all the time and these potentially offer great benefits for improving the quality of health care for patients. Many of these new technologies need to be tested using large amounts of patient data to ensure they are effective. These new technologies include apps being developed outside of the NHS. But innovation isn't always driven by technology: new methods for evaluating proposed services are innovative too, and require patient data.

For example, our work examining the impact of providing enhanced support for care home residents in Rushcliffe<sup>2</sup>, demonstrates the requirement for good quality patient data.

The Health Foundation recognises that gaining access to patient data for innovative purposes can be difficult. Often a clear benefit from using data can be difficult to predict. Some innovations will fail, while others succeed. The current process for accessing data is predicated on the assumption that we know in advance what the results and the benefits of use of the data will be. Testing innovations is often less clear.

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<sup>2</sup> Health Foundation. The impact of providing enhanced support for care home residents in Rushcliffe.

<https://www.health.org.uk/publications/the-impact-of-providing-enhanced-support-for-care-home-residents-in-rushcliffe>

Therefore, we think the NDG could play a lead role to enable new technologies to be evaluated effectively<sup>3</sup> and guide organisations that could supply data about how to create a better environment for testing innovations using patient data. An example would be the use of data for experimentation which upholds the privacy of patients, such as using synthetic data, though other options are likely to emerge. The NDG could provide guidance so that data suppliers could feel comfortable enabling access to data in this way.

Dialogue with the public will be essential to secure and maintain trust about how data are used to test new technologies. We've heard about a number of situations where data were used without patients knowing about it until later; this can hold back development as the public become frightened about how their data are used.

In addition, we've heard of cases where the public have consented for their data to be linked, however, information governance rules have blocked progress. This is equally unethical, and we refer to the Seventh Caldicott Principle later in this response.

The NDG, working together with organisations such as Understanding Patient Data, could play a role to help organisations engage with the public as part of the design process for testing and developing technologies with patient data.

**Are the outlined areas of NDG interest the right ones for the NDG under this priority? (Please tell us if there are other areas we should be looking at under this theme, or if you think others would be better placed to do the work)**

The Health Foundation agrees that the areas of interest already identified by the NDG are right to pursue. In addition, we think the NDG could work with data providers to consider data access processes that would facilitate use of patient data to test and evaluate innovations that have the potential to improve the quality of patients' experiences. Our Improvement team have undertaken work in this area, and we would be happy to follow up with the NDG in this area.

**What would you like to see the NDG do in this area?**

The Health Foundation would like to NDG to provide guidance to data providers to ensure that data access decisions to test innovations are clearer and more straightforward, even in cases where a clear outcome and public benefit from the innovation is not immediately evident.

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<sup>3</sup>Health Foundation. Making technology work for the NHS and its patients <https://www.health.org.uk/news-and-comment/blogs/making-technology-work-for-the-nhs-and-its-patients>

## **Priority 4: Safeguarding a confidential health and care system**

### **Should Safeguarding a confidential health and care system be one of the NDG's top priorities?**

This area is always of paramount importance and safeguarding is important for maintaining trust in the use of data about patients. For this reason, it should continue to be a priority for the NDG.

Processes for acquiring data remain unclear and slow. This can provide strain on the safeguarding mechanisms in place to protect patient data. For this reason, we believe the NDG plays a vital role.

Streamlined methods for applying and accessing data are possible, and can still fit in with the public's expectations. For a number of years, the ONS Microdata Release Panel has granted access to personal data with relative efficiency, abiding by legal and public requirements for safe data access. We see little reason why the health sector cannot follow.

### **Are the outlined areas of NDG interest the right ones for the NDG under this priority? (Please tell us if there are other areas we should be looking at under this theme, or if you think others would be better placed to do the work)**

The Health Foundation recognises that the distinction between common law duty of confidentiality and data protection legislation can be confusing. We agree that a way to explain these concepts to clinicians and patients is important.

However, these terms interplay with requests to access data. For example, applications to the HRA's Confidentiality Advisory Group require researchers to make a reasonable attempt to 'notify' patients that common law duty of confidentiality may be set aside. This differs from acting transparently about the use of data, which is a requirement of data protection legislation.

Distinctions such as these often aren't clear and can be seen as arcane when researchers try to access confidential patient data to undertake projects that would benefit health care in the future. As a result, the data access process is opaque, when it could be simplified. Therefore, we think that clarification of these terms should be extended to include researchers and data providers, in addition to clinicians and patients.

Furthermore, processes should be streamlined so that common law and data protection legislation are not treated separately. The Health Foundation would be happy to advise further on this; our staff have experience of applying to access data from within the health sector and beyond, and we can point to where legislation has been streamlined with great success.

### **What would you like to see the NDG do in this area? Additional consultation questions**

The Health Foundation would like the NDG to go beyond thinking about clarifying the terms 'common law duty of confidentiality' and the data protection concepts, and work with data providers to facilitate data access which brings these legal areas together.

However, we think it is worth noting that while streamlining these concepts is important, other aspects of data protection are worth considering too. For instance, the recently implemented GDPR contains requirements for explaining how data will be used in automation, where such automation makes decisions on behalf of individuals. As new technologies develop, we can foresee when decisions about our health care are automated, based on our own data. This is one of a number of areas that the NDG can play a role with respect to safeguarding our health data.

**Looking at all the priorities outlined, are there other areas of work that you would suggest for the NDG?**

Improving data access

The Health Foundation acquires data about patients from a number of organisations to support its work. Although we acknowledge that work has been done to improve data access, we and other organisations continue to experience inconsistent approaches to approving access to patient data by these organisations, coupled with lengthy delays. At best, this situation is time-consuming and expensive; and at worst, projects are unable to be undertaken, and the benefits from analysing patient data will not be realised by policymakers and the health service. The NDG could play a vitally important role to assist establishing a framework for approving the release of patient data for purposes beyond direct care, which could be adopted by organisations in the health service that provide access to these data.

In addition, we know that the health and care sector across the UK is tasked with providing high quality care to a growing population with increased health and care needs. Some of this increase is due to an ageing population, but it is also due to the increasing number of individuals living with multiple conditions. This population has grown rapidly over the past decade<sup>4</sup> and with current demographic trends (as well as trends in risk factors such as obesity) it will continue to grow.<sup>5</sup>

At the same time, economic inequality has grown across the UK, and improvements in life expectancy have stalled. As a result, there is increasing recognition of the important impact that wider determinants have on our health, the imperative for health policymakers to address the inequalities in health outcomes, and the need for linked health and other data to generate insights that aid strategy and policy in health, as well as health care.

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<sup>4</sup> Health Foundation. Emergency hospital admissions in England. <https://www.health.org.uk/publications/emergency-hospital-admissions-in-england-which-may-be-avoidable-and-how>

<sup>5</sup> Health Foundation and the Institute of Fiscal Studies. Securing the Future. <https://www.ifs.org.uk/publications/12994>

With the introduction of primary care networks and greater emphasis on the NHS working in partnership with other organisations to reduce inequalities in health, we need new data linkages so that all stakeholders can understand how these partnerships are working for more disadvantaged communities. Linkage of electronic health records to data from local authorities, mental health providers in schools, and voluntary and other providers of health and care services will help us understand inequalities in access, care quality and outcomes across the full range of services that can impact health.

Seventh Caldicott Principle: the duty to share information can be as important as the duty to protect patient confidentiality

While the focus on safeguarding is understandable, we encourage the NDG to consider the seventh Caldicott principle<sup>6</sup>, which is about ensuring that data can be shared. IG is often implemented as a barrier to data access and sharing, when in fact, it can act as an enabler. The apparatus and framework for ensuring data can be safeguarded exists. What is evident is that too often data aren't shared as they could be, and this is detrimental to efforts to improve the quality of care received by patients.

Data in other sectors: the Digital Economy Act

In 2018, the Digital Economy Act came into effect. This provided a legal gateway to enable government agencies to share personal data to improve services. It included a provision for enabling the combining of data from different agencies for research purposes.

Our understanding is that the provisions of the Digital Economy Act excludes health data. While other data (e.g. education and justice data) can be combined, there is no straightforward legal gateway to enable health data to be combined with other sources.

We would like the NDG to facilitate discussion for enabling health data to be included in amended legislation

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<sup>6</sup>Information Governance Toolkit. <https://www.igt.hscic.gov.uk/Caldicott2Principles.aspx>

**For further information:**

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