

National Data Guardian for Health and Social Care: a consultation on priorities

Response by Understanding Patient Data

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Summary

- The National Data Guardian for Health and Social Care (NDG) has identified four important priorities for the health, care and research system. With the exception of ‘innovation’, these priorities represent long-standing issues that mainly require focus on implementation rather than new policy development.
- With a scope across England, the NDG has an important role to play in gaining an overview of the current state of health data management and use, which is highly fragmented and inconsistent.
- Working through these priorities, the NDG should be a champion of best practice, highlighting the tremendous opportunities afforded by better, responsible use of data as well as providing guidance in areas that require improvement.

Introduction

Understanding Patient Data (UPD) are pleased to respond to this consultation. Placing the NDG on a statutory footing is a substantial step towards bringing coherence and trustworthiness to the health and care system in how it manages and protects patient data. It enhances the opportunity to provide substantive, authoritative advice and to hold all parts of the system to account. The NDG should work with the devolved nations to create further join-up across the UK.

We agree that the priorities set out by the National Data Guardian (NDG) are vital to address. Given the resources that will be needed, it may be advisable to consider focus within the priorities in terms of immediate, medium and longer-term objectives. We also urge the NDG to consider the additional challenges that integrating health and social care will introduce to the safe, appropriate management of patient and care data.

Most of these priorities are not novel policy challenges, but progress in addressing them across the health and care system has been slow. Where possible the NDG should focus on practical challenges to implementation and provide clarity across the system where it is currently absent. We look forward to working further with the NDG as approaches to these key issues are developed.

Encouraging access and control: individuals and their health and care data

The NDG should scope out the prevalence of patient records' accessibility in practice, and investigate practical barriers to enabling better patient choice and control over data about them. This is necessary for a more coherent dialogue about what forms of patient access and control are both feasible and desirable.

1. Patients must have greater and easier access to their health records; this has been established as a key principle of patient empowerment and choice for several years but it is still not the default in many places. The NDG and Caldicott Guardians have an important role to play in understanding where and how this principle is being applied in practice and what the barriers to patient access are.
2. Patients should be able to see who has accessed information from their health and care record as part of providing them with individual care. They should also have better access to meaningful information about how data about them is used beyond their individual care, in research and planning. Although there are pockets of good practice, information provision is patchy. The NDG should identify barriers to implementation and work with the health professional community to establish best practice.
3. For example, the NDG could convene stakeholders to define technical and practical limits to patients' access to information about how data from their records is used. This should take into account the type of data it is feasible to track and what capacity there is to enable useful, useable audit trails for patients.
4. When considering "models of control", the NDG should note that existing public attitudes work finds that patients have low awareness of the current system and how health data is used beyond individual care. Patients are often unlikely to be aware of, for example, how population health management and research leads to health and service benefits. These important functions may be undermined by models based on full individual control of all aspects of data use.
5. The NDG should draw on existing deliberative work with publics and patients exploring these questions. These studies often identify nuanced, complex views that emerge when participants learn more about how data is used in practice, what the risks are and what the burdens on individuals may be with additional levels of individual control.

Using patient data in innovation: a dialogue with the public

The NDG should champion increased, meaningful dialogue with publics on innovations that use patient data as part of their development, testing and evaluation. Insights from this work should help shape the rules for how data can be used in innovation, to ensure fair benefits for the NHS and patients.

6. Different groups of patients and publics will have different expectations and boundaries on topics such as the value of patient data, privacy, fairness and data linking across different sources. The NDG should seek a strong grasp of the variations in views and

attitudes from different publics, especially including those who may be digitally excluded or vulnerable.

7. Ongoing dialogue is critically important; as the NDG notes it should not be a one-off conversation. Research into people's views, expectations and concerns has also not kept pace with technological innovation. At the same time, however, it is important that people can trust the basic principles and parameters of data use and that these will not constantly change and evolve.
8. Health data innovation will happen outside the remit of the NDG. It will be important to be clear for patients and health professionals where the NDG does and does not have jurisdiction or protective responsibilities, for example on data or apps that may be about health but that do not sit within the health and care system.
9. There is rich potential for linking data across multiple sources to yield new insights. Deliberative public research is needed to establish the social licence for innovation that links health data with other sources of data to support care, service provision and research.
10. The NDG should work with the Ada Lovelace Institute, Health Data Research UK, Office for Life Sciences, the Centre for Data Ethics and Innovation, the Council of Caldicott Guardians and professional regulatory bodies as well as NHS bodies to identify where advice and guidance to the health and care system is most urgently needed. This will ensure data is used responsibly and appropriately in health data innovation.

Getting the basics right: information sharing for individual care

It is crucial that data is accurate, available for the right purpose at the right time, joined up and shared to support individual care. The NDG must address the practical barriers to health and care staff using and sharing data by helping to create more uniform interpretations of what is and is not appropriate across all NHS and care organisations.

11. Getting the basics right in individual care is crucial. Despite Dame Fiona's work to provide clarity in previous Caldicott Reviews, misunderstandings persist about what data it is appropriate to share and when – in part because of risk aversion and fears about breaching data protection law. This will become more pressing as health and social care are integrated. It is imperative the NDG establishes how to address the cultural, technical and logistical blockers here for health and care professionals.
12. The NDG should investigate variations across the country and champion good practice, as well as working to understand barriers to improvement. For example, what constitutes direct or individual care is contested, especially in relation to service improvement and product development.
13. If data is better used to support individual care, this lays the foundations for a learning health system that can constantly iterate, provide better services and enable vital research that can save and improve lives. The NDG could set out a clear ambition here

for how data could and should be used to both deliver and improve care, creating new understanding and advocates for responsible uses of data.

Safeguarding a confidential health and care system

The NDG should work to improve the way the legal frameworks for data use are understood. This should include identifying where data sharing practices are reasonable and unreasonable, within and beyond the NHS.

14. The NDG can play a leading role in establishing how the Data Protection Act (2018) and the Common Law Duty of Confidence should interact and be interpreted together to determine appropriate, lawful uses and management of data. This includes working with the ICO to establish the bounds of 'personal data' in health and research settings and the appropriate governance for "de-identified" data that still constitutes personal data under GDPR.
15. As an independent voice, the NDG should also look beyond the health and care system to define the circumstances under which access to patient data across government departments is reasonable and acceptable, and where such sharing may threaten to undermine public confidence. This will provide assurance about the NDG's role as a guardian of public interests and trust in the management and use of the nation's health data.