



# **NATIONAL INFORMATION BOARD**

## **Personalised Health and Care 2020**

### **WORK STREAM 4 ROADMAP**

#### **Build and sustain public trust**

**Deliver roadmap to consent based information sharing  
and assurance of safeguards**

September 2015

Final Version



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## 1 CONTEXT

### 1.1 Background

Data collected by the health and care system is a rich resource and has enormous potential to drive improvements in health and care and to improve outcomes for UK patients and the public. Thousands of interactions between patients and health and care professionals take place every day and each one involves the collection or use of data. Fully utilising this data will assist commissioners and healthcare professionals to commission and run health and care services more efficiently, to evaluate the effectiveness of those services, and to regulate their safety. Furthermore, data can be used to improve the quality of public health monitoring, resulting in benefits such as greater health literacy, improvements in lifestyle and wellbeing, disease prevention, and keeping citizens safe from communicable and environmental hazards. The Summary Care Record (SCR) is an example of how data is being used to improve the quality of patient care. SCR is an electronic health record of key information taken from individual GP records. It provides authorised healthcare staff with faster, secure access to essential information about patients when unplanned care is needed or when GP practices are closed. As of May 2015 over 54.5 million people have an SCR, which is 96% of the population.

A further use of data is to ensure that UK citizens can access the newest and most effective treatments. The UK is already a world leader in health research and is known for innovative projects which provide tangible and substantial benefits to patients. The [UK Biobank](#) aims to improve the prevention, diagnosis and treatment of a wide range of serious and life-threatening illnesses by following the health of 500,000 adults across the country. [The 100,000 Genomes Project](#) will lead to better treatments and earlier diagnosis for patients for generations to come. Based on the consent of NHS patients with cancer or a rare disease, their genome and clinical data will be used for ethical research purposes. The project is already returning results; two families have now been diagnosed with rare diseases as part of a project at Newcastle Hospitals and University and will therefore be able to receive effective and personalised treatment.

### 1.2 Use of Data

There are two types of data: (a) data which identifies an individual or could be used to do so (effectively, any person-level data); and (b) aggregated and anonymised data.

There are four principal reasons for using health and care data:

- To support an individual's direct care;
- To run the NHS and health and care system more effectively and efficiently in order to achieve higher quality outcomes;
- To promote research, including to develop innovative new medicines, treatments and services; and
- To protect and improve health and reduce health inequalities.

The need for better use of data and technology was highlighted in the NHS Five Year Forward View as a tool to help address the health and wellbeing gap, the care and quality gap, and the funding and efficiency gap.



However, there are ethical, legal, professional, technical, and behavioural barriers to overcome before the UK's health and care data can be fully utilised for the purposes described above and there has been concern raised in the media about the use of data. This underpinning work stream is directed at addressing the perceived issue of public trust and aims to ensure that public and professional confidence can be earned and sustained in order to encourage data sharing. A key part of this will be developing a consistent consent model to be used across health and care. In effect, the health and care system has to demonstrate that the public can trust it with data about them. This trust is a prerequisite for the success of the NIB, therefore close engagement between all domains is necessary.

## 2 RESEARCH AND EVIDENCE

A number of studies provide valuable insight into the questions around the use of data:

- The Nuffield Council on Bioethics published *[The collection, linking and use of data in biomedical research and health care: ethical issues](#)* in February 2015, considering the relationship between public and private interest, and differing public perceptions and concern about data use;
- Weale and Clarke published *[Information Governance in Health](#)* in 2011, considering the debate of how best to reconcile the benefits of improved health services and research with social values including consent, privacy, and fairness and reciprocity; and
- A 2013 [study by the OECD](#) argued that 'it makes economic and ethical sense to use this data as much as possible: to improve population health and to improve the effectiveness, safety and patient-centeredness of health care systems'.

The Wellcome Trust found that the public have "no/very few objections to medical data being used for the 'general good' (perceived as helping to find cures and causes), provided commercial gain is not the priority".<sup>1</sup> [Work conducted by Ipsos MORI](#) also suggested that GP surgeries, the NHS, academic researchers and universities are the most trusted institutions, but often feel uneasy about its use by external parties such as insurers, entrepreneurs and other government departments. The HSCIC may only disseminate information where there is a clear purpose for the provision of health care, adult social care or the promotion of health, and not for solely commercial purposes, such as insurance.

Work is needed to earn the public's trust in the health and care system's ability to manage personal confidential data safely and securely. A balance must be found between the desire to use data for the public good and the need to keep that data safe and secure. Throughout the summer of 2015, the work stream has attended or run events addressing these questions, including four NIB regional events and a session at the NHS Expo. A number of important messages have been learnt:

- The importance of being honest and using laymen's terms when communicating as well as being realistic about what can practically be delivered.
- The health and care system must demonstrate to patients and service users that it is trustworthy through competence, honesty and reliability.

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<sup>1</sup> [http://www.wellcome.ac.uk/stellent/groups/corporatesite/@msh\\_grants/documents/web\\_document/wtp053205.pdf](http://www.wellcome.ac.uk/stellent/groups/corporatesite/@msh_grants/documents/web_document/wtp053205.pdf)



- Demonstrating trustworthiness requires a clear, consistent and transparent explanation of the uses to which this information will be put and the benefits for patients and service users.

Ultimately, the health and care system needs to provide a clear vision to the public that transforms the relationship between the state and the citizen about their health and care data. This is not merely a technical exercise to counter negative media attention; substantial change and long-term work is needed to deliver the benefits of data use.

## 3 BUILDING THE PICTURE FOR DELIVERY

### 3.1 Public Dialogue – The Key

The priority for this work stream, and a prerequisite for the success of other domains, is to get the public dialogue right.

The Nuffield Council on Bioethics' held a roundtable event on 19<sup>th</sup> June 2015 which discussed securing the use of health and care data in a way that sustains public and professional trust. The event provided an opportunity for leaders in the NHS and health and care system to meet informed and influential stakeholders, to engage in debate and to generate options for demonstrating trustworthiness in the use of health and care data. Ten key messages were taken from the event, which include the importance of trustworthiness, earning trust in an ongoing process, the importance of nationally consistent messages alongside local delivery, and the importance of engaging professionals and third sector partners who work with members of the public as they will play a crucial role in earning public trust.

In order to ensure this work stream incorporates a local perspective, sessions were also held at the NIB regional roadshows throughout July 2015. These provided participants with an introduction to the work stream and the issues it is attempting to address in its bid to demonstrate trustworthiness in the way the health and care system uses data. Attendees were also able to express their views - mindful of their local situation - on the questions that WS4 is considering and the work it has undertaken so far. Lessons learned at these events have informed future planning.

These events provided initial insight into people's views, especially those of health and care professionals. Additional engagement, in particular with the public, will be used to inform the independent review, commissioned by the Secretary of State to assure the security of confidential medical information.

### 3.2 National Data Guardian for Health and Care

If patients and service users are to be confident in allowing the health and care system to use their data, there needs to be robust safeguards to ensure that this is done in a lawful and appropriate way. An independent and trusted 'challenge' function is essential. The National Data Guardian for health and care (NDG) was established by the Secretary of State in November 2014, with a remit to speak without fear or favour about the safe use of personal health and care information.

Dame Fiona Caldicott and the Independent Information Governance Oversight Panel (IIGOP) have already, without recourse to legislation, built a strong reputation as an effective and authoritative voice.



The Government has launched a public consultation seeking views on the National Data Guardian's role and functions including how it relates to the Information Commissioner's Office, with the aim of publishing a response to this consultation early in 2016. ([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/461993/Consultation\\_ND\\_Guardian\\_accessible.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/461993/Consultation_ND_Guardian_accessible.pdf))

Primary legislation will most likely be used to place the independent National Data Guardian role on a statutory basis, providing public reassurance that health and care data is being held and used safely.

### 3.3 Preference Models

Patients and the public should have the confidence that their preferences for the use of their data are being upheld wherever possible, and health and care professionals should be confident in the legality of using a patient's data for their own care. The use of personal data to support direct care is already lawful, albeit on the basis of the common law principles of consent. Reliance on the common law, combined with a lack of training in information governance, can lead to a 'risk-averse' approach preventing health and care staff from cooperating as they should for the benefit of patients.

The Health and Social Care (Safety and Quality) Act 2015 places a duty on health and adult social care providers to share information about a person's care along their care pathway with other health and care professionals. Clinicians providing a person's care and treatment will have the information they need at their fingertips so they can treat that person more effectively.

Given the importance of the issues within this work stream an independent review has been commissioned by the Secretary of State to assure the security of confidential medical information. This will include a review of the effectiveness of current approaches to cyber security capability in NHS organisations in relation to their handling of patient confidential data to be carried out by the Care Quality Commission (CQC).

The National Data Guardian for health and care, Dame Fiona Caldicott, will contribute to this review by developing clear guidelines on data security against which every NHS and care organisation will be held to account. The work will be completed in January with recommendations on how the new guidelines can be assured through CQC inspections and NHS England commissioning processes. Dame Fiona Caldicott will also provide recommendations on a new consent model which will make it absolutely clear to patients, and users of care, when data about them will be used, and in what circumstances they can opt out.

Work has also been undertaken to look at some of the dependencies that the implementation of a system wide preferences model will place on other NIB work streams.

The HSCIC will work to develop the infrastructure for recording patients' preferences for the use of their data based on the model that emerges from the CQC/Dame Fiona Caldicott review.

### 3.4 Information and Cyber Security

The Department of Health and the HSCIC are working with NHS England, Monitor and the Trust Development Authority (plus other ALBs and relevant professional bodies) to make sure that organisations, systems and patient data are safe and secure from the risk of malware and other potential forms of cyber-attack. The Information Security and Risk Board (ISRB) was established



in April, and comprises of senior officials from across the health and care system and Cabinet Office. The principal focus will be on information and system security.

Dame Fiona's work will lead to a set of key cyber security standards to be applied across the health and care system. Organisations will be held to account either via the CQC inspection process or via NHS England commissioning guidance.

A key tool to deal proactively and effectively with cyber-security risks will be the CareCERT facility (the health and care Emergency Response team, with alerting, response and support capability which is to be established by the HSCIC). The aim of CareCERT is to provide a proactive service which enables rapid, controlled dissemination of information about, and fixes to, cyber threats identified within public sector systems. It will also be used to coordinate the national responses to cyber threats in health and care.

Within our current care system, the information security culture is diverse and more work is needed to ensure consistency of risk assessment, and mitigating treatment. It is essential that the issue of behavioural change at board-level is addressed.

### 3.5 Information Governance

Unlike other countries such as [Sweden](#), where Information Governance is relatively straightforward, the system in England is complex, with a web of the common law, multiple Acts of Parliament, and decades' worth of Government policy and commitments. The resulting uncertainty means data is not always used effectively to improve care. This work stream is an opportunity to simplify this system and strengthen its role in assuring public confidence.

The Information Governance Alliance (IGA) was set up in July 2014 in response to a request from the IIGOP and the National Data Guardian. The IGA brings together resources from member organisations to consolidate specialist knowledge, provide a single source of authoritative and credible guidance and to establish a national information governance network.

The Information Governance (IG) Toolkit provides a roadmap for achieving excellent information governance. It is also a performance assessment, incident reporting and management tool satisfying the Cabinet Office requirement for DH to provide assurance that all parts of the NHS are meeting mandated data handling standards.

The IG Toolkit needs to be updated to meet the developing demands of the health and care system. The HSCIC will work to refresh the IG Toolkit in stages to ensure that it is easy to use and relevant to the information needs of health and care organisations and that it takes full account of the outcomes from the CQC-led review of cyber security and Dame Fiona Caldicott's subsequent recommendations. It will also work closely with the IGA to create a single, authoritative source of Information Governance support and guidance for the health and care system. This will include refreshing the training material provided by the HSCIC to health and care organisations.



## 4 BENEFITS

Work Stream 4 is not expected to have explicit cash-releasing quantifiable benefits. Instead, this work stream will help ‘unlock’ the potential benefits of other domains. Public trust is a prerequisite for the success of all other domains and therefore all of the benefits are linked.

In particular, Work Stream 4 will enable the benefits described in the following roadmaps:

- providing patients and the public with digital access to the health and care information and transactions
- providing citizens with access to an accredited set of NHS and social care “apps”
- setting the commissioning and regulatory roadmap for implementing digital standards (including agreement on the standards)
- developing a roadmap for comprehensive data on the quality, efficiency, and equity of health and care services for secondary uses (i.e. all uses that are not direct care)
- bringing forward life-saving treatments and supporting innovation and growth.

Patients, citizens, carers and clinicians will all benefit:

### Patients/Carers

- Patients will have confidence that their personal records are only being accessed by the staff who need access in order to deliver their care.
- Providing data, in accordance with people’s preferences, to researchers and organisations who undertake academic or health service improvement research to develop new medicines, treatments and services will improve patient care.
- When health and social care professionals can share and link information, people only have to tell their story once rather than repeating it to every new professional they see.
- Information can shed light on how well the local health and social care system is working for the people it aims to help, and this can result in smarter commissioning and improved local health and social care services.
- Patient access to their information will allow them to identify any mistakes in their records and avoid any treatment errors as a result.
- Using digital and online services can simplify the more routine aspects of care, such as booking appointments, requesting repeat prescriptions, or self-assessment for social care.
- Enabling data use will allow patients to manage their own health and care better.
- Carers could be able to access services and health and care records online, according to the access authorised by the person/people for whom they care, helping them to carry out their responsibilities safely, conveniently and effectively.
- Advances in technology can also help more individuals manage illnesses or long term conditions and to continue living in their own homes, using devices and equipment that can help monitor things such as blood pressure and glucose levels, thus reducing the number of visits they need to make to GPs and hospitals.





### Citizens

- Improved data will result in smarter commissioning which will mean improved health outcomes for citizens and service users, and more efficient and equitable use of taxpayer money.
- Citizens will be provided with transparent information about how health and care services are using their data and will therefore have increased trust and confidence in these institutions.
- Public health benefits will include better health literacy, improved lifestyle and wellbeing, disease prevention, and keeping citizens safe from communicable and environmental hazards.

### Clinicians/ Professionals

- Care Professionals will have the ability to access high quality data on patient safety, patient experience, and the outcomes that matter to patients, including patient reported outcome measures (PROMs).
- Professionals will be able to collaborate as a care-giving team, without any uncertainty about the legality or consequences of sharing data with other professionals who are delivering care within a patient's care pathway.
- Clinicians will have the ability to access data on the clinical activities each care professional has been involved in so that they are able to benchmark themselves and generate evidence for revalidation and for continuous improvement.

### Commissioners/ Providers

- The use of data will be a key source of insight in identifying efficiency opportunities from improved coordination, reduced duplication and more proactive care management.
- Data and technology can also address the three overarching issues within the NHS: the health and wellbeing gap, the care and quality gap, and the funding and efficiency gap.
- Understanding the health needs of a population means that funding can be allocated more fairly and therefore health inequalities can be reduced. It also means that it is easier to design and plan better health and care services and for these services to be safely evaluated, regulated and improved.



## APPENDIX A: TIMELINE FOR WORK STREAM 4 ROADMAP

