

**Paper Ref: NIB 0403-009**

**BOARD PAPER – National Information Board Leadership Meeting**

**MARCH 2015**

**Title:** Work stream 4: Build and sustain public trust: Deliver roadmap to consent based information sharing and assurance of safeguards

**Purpose of paper:**

- To outline the objectives and plans of the work stream

**Actions required by the Leadership Group:**

- To note the report.
- To ratify the plans set out in this paper

## CONTEXT AND OBJECTIVES

1. The work stream brings together programmes of work which, taken together will help ensure that citizens' health data and information will be looked after and managed securely, will be used – as far as is possible – only with the consent of the individual, and that there is transparent oversight of how information is used. This work will help to build public trust and confidence in the way the health and care system uses data, to enable the improvements in safety, quality and efficiency of care, which all depend on the availability and proper use of information.
2. The high level objective of the work stream is to support the ability of the health and care system to collect and use data to improve outcomes by ensuring that health and care data about an individual is collected and held safely and that the public has confidence in the way that information is used.
3. The work stream will be responsible for the commitments set out on page 41 of the National Information Board (NIB) framework:
  - Dame Fiona Caldicott, supported by her current Independent Information Governance Oversight Panel (IIGOP), will take on the role of National Data Guardian for health and care, with a remit to provide public and transparent scrutiny and challenge about the safe use of personal health and care information.
  - DH will, at the first suitable legislative opportunity, seek to place the role of the National Data Guardian on a statutory footing. In doing so, DH will consult on what powers the National Data Guardian should have and how those powers should be exercised. This will include consideration of any sanctions that the National Data Guardian should be able to bring to bear on those who misuse personal health and care information.
  - Under the auspices of the NIB and the National Data Guardian, a working group will carry out a wide-ranging public consultation on how the care system should handle the dissemination and use of sensitive data. This will develop proposals that enable citizens to access a transparent audit that records the uses made of their patient data for secondary purposes and details the benefits for health and care that have resulted.
  - By April 2016 NIB will publish, in partnership with civil society and patient leaders, a roadmap for moving to a whole-system, consent-based approach, which respects citizens' preferences and objections about how their personal and confidential data is used, with the goal of implementing that approach by December 2020. This roadmap will continue to recognise

that there are certain circumstances where securing explicit consent by a citizen is not operationally possible, nor desirable on every occasion, for example in the management of notifiable and infectious diseases. It may also not support the individual's best interests, for example in the care and support of vulnerable adults.

- Based on the work already commissioned by the Secretary of State for Health, the Health and Social Care Information Centre (HSCIC) will publish by October 2015 enhanced data security standards and requirements for all publicly funded providers of care.
- The Department of Health (DH) will develop proposals to further strengthen the role, responsibilities and functions of senior information risk owner and information asset owners in the health and care system.
- The HSCIC will, by October 2015, relaunch the Information Governance Toolkit to reflect enhanced information governance and data security requirements.

## **DELIVERY WORK PLAN**

4. Work stream 4 will deliver a range of outputs to different timescales:
5. The National Data Guardian (NDG) role will be established quickly. It will be initially hosted by the HSCIC, pending the legislative opportunity which allows the role to be placed on a statutory footing. There will be a consultation process in 2015 on the functions and powers of the NDG.
6. It is at this stage difficult to identify the deliverables associated with the public consultation on the use of health and care data. The work will begin in 2015 and is expected to include deliberative groups to discuss complex issues and engagement events, as well as use of existing organisations and ways to listen. There will also be a need to listen to professional audiences.
7. The work on consent will deliver, firstly, a 'roadmap' for achieving a system that can record and share consent decisions and can provide information on the use to which an individual's data has been put. Over the longer term, digital solutions will be developed that automate as far as possible these processes.
8. On data and security, there will be a range of products:
  - a. Enhanced oversight and improved governance of cyber and information security across the health and care system
  - b. Published information standards relating to data security, for deployment by all

- c. A revised Information Governance Assessment Framework for the health and care system, including an updated and enhanced Information Governance Toolkit
- d. A suite of enhanced cyber security tools developed by the HSCIC.

## **GOVERNANCE**

9. A programme board, drawn from National Information Board (NIB) members, including independent members and the clinical reference group, is being established to oversee the delivery of work stream 4. Members will include representatives of the following:
  - Medicines and Healthcare products Regulatory Agency
  - Health Research Authority
  - Care Quality Commission
  - Health and Social Care Information Centre
  - Public Health England
  - Trust Development Authority
  - Human Fertilisation & Embryology Authority
  - National Data Guardian
  - Independent NIB member
  - Clinical Reference Group
10. The programme board is chaired by Una O'Brien, Permanent Secretary at the Department of Health.
11. The work stream is led by Mark Davies, Director of Informatics and Digital Strategy at the Department of Health and Prof Martin Severs, Clinical Professional Lead at the Health and Social Care Information Centre.

## **HIGH LEVEL CHALLENGES**

12. There are complex issues to debate but the need to build an understanding and consensus between citizens and the system on how personal information is used for the benefit of service users and the wider community. This will be addressed through a carefully designed public consultation and wider engagement approach across the work stream.
13. The emergence of genomics requires a conversation about what kind of consent is appropriate by 2020. The work stream will investigate a strand of work to be led by an ethicist.
14. A register of detailed project risks is being managed by the work stream programme office.

## **DECISIONS REQUIRED OF THE LEADERSHIP GROUP**

15. Work stream 4 requests the Leadership Group make the following decisions:

**Ratify the plans set out in this paper**