

Paper Ref: NIB 0403 – 003

BOARD PAPER – National Information Board Leadership Meeting

Title: Work stream 1.1: Enable me to make the right health and care choices: providing patients and the public with digital access to health and care information and transactions

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

The overall purpose of work stream 1.1 is to support people in making the right health and care choices, through digital access to health and care information and transactions. The work stream will look at how digital services can support prevention and self-care, improve quality and contribute to future service sustainability.

The work stream will be responsible for the commitments set out on page 23-25 of the Framework:

- From March 2018 all individuals will be enabled to view their care records and to record their own comments and preferences on their record, with access through multiple routes including NHS Choices. Initially, this will focus on data held by NHS providers (primary care, acute, community and mental health), but it will be progressively extended to cover other care settings, taking account of the work that local authorities are progressing in regard to personal records. This will create the opportunity for individuals to create and manage their own personal care record. The NIB will publish a roadmap for implementation by June 2015, which will then be integrated into commissioning and regulatory arrangements, where appropriate.
- We will enable all citizens to have a single point of access to all transaction services, including booking appointments and online repeat prescriptions for all care services. This will build on NHS England's existing programme, in collaboration with the government's wider programme led by the Cabinet Office. NHS England, with HSCIC, will publish proposals by June 2015 to consolidate NHS e-Referrals, appointment booking and repeat prescription ordering with NHS Choices, as a basis for providing a single, common portal for all care providers and service users. NHS Choices will be developed to provide a core common platform for all care providers and will be capable of customisation to reflect the specific needs of different localities and communities.
- NHS England, with DH, Public Health England (PHE) and the HSCIC, will publish proposals by September 2015 for linking the 111 service with NHS Choices and other public information channels to create a seamless public information service.
- The HSCIC will publish by 1 April 2015 the roadmap and the standards that care organisations will need to meet in order to be able to access core transaction systems, including Spine and NHS e-Referrals. vii. NHS England will pilot individual digital 'care' accounts in which patients hold not just their records, as above, but also a personal budget, as part of its programme to offer Integrated Personal Commissioning from April 2015.
- The NIB will oversee the launch of a national experiment to give patients a personalised, mobile care record which they control and can edit but which is also available in real time to their clinicians. The HSCIC, PHE and NHS England will, together, establish a national digital standard for people at the end of their life – building on the success of Coordinate My Care in London – (see case study) – so that their care preferences are respected. For parents of newborns, we will encourage digitisation of the personal child health record (the 'red book').

- DH, NHS England and the HSCIC, in partnership with the voluntary and independent sectors, will sponsor initiatives to develop and provide technology and data services, to support new ways of delivering care services. These will focus on people with learning disabilities, young offenders and dementia carers.
- The NIB will establish a working group with a broad membership, including users and stakeholders, to advise on the impact of data and technology developments on inclusion and equity across the care system, and build on existing programmes, like that between NHS England and the Tinder Foundation.

WORK PLAN

A document will be produced by June 2015 that outlines the roadmap to 2020.

The work will be taken forward in the following way:

- **Design** – through research, engagement and co-production with patients, carers and citizens we will define how digital delivery can better support the health and care needs of the population and help improve outcomes and engage a range of stakeholders, including local government, clinical commissioning groups, clinicians and industry about the implications.
- **Delivery** – we will set out the roadmap of what needs to take place both nationally and locally, including the roles of other stakeholders to deliver on the key needs identified. This will include an assessment of the current portfolio as well as local initiatives. It will also outline potential future functionality of the national programmes around information and transactions. The work will specifically include agreeing an approach for citizen identity assurance across health and care for personal access to health and care records and apps.
- **Influence** – we will set a vision to help drive development of local digital services across the whole health and care system to support improved health and wellbeing for the population. This recognises the role that local commissioners play, alongside that of the independent and voluntary sector.

Deliverable	Timing
Set up of work stream team	Feb 2015
Arrange steering group meetings	Feb 2015
Arrange and hold meeting with lay members	Feb 2015
Research programme (see below)	Feb – April 2015
Stakeholder engagement event	March/April
Influence and engagement with local systems and stakeholders	Feb – June
Engagement with the local delivery work stream and local digital	Feb 2015
Engagement with the clinical reference group	Feb 2015
Agreement of work programmes on experiments – on	Feb 2015

End of Life, Maternity and Mental Health	
Workshop to review research and test ideas with key stakeholder groups	April 2015
Review of current national portfolio and generation of core recommendations	Feb – May 2015
Agreement on scope and approach for citizen identity programme	May 2015
Specific working group meeting to consider impact of proposals on inclusion and equity	May 2015
Consultation and agreement on scope of personal health record	May 2015
Scoping of the technology and data services to support people with learning disabilities, young offenders and dementia carers	June 2015
Final roadmap	June 2015

The work stream will work closely with the 'Local Delivery' work stream, Pioneers/ Vanguard, Local Digital team and other key representative groups and networks (e.g. representing clinical commissioning groups, providers and local government, patient organisations, Chief Clinical Informatics Officers and Chief Information Officers and industry) to shape the programme as it develops.

The Strategic Clinical Reference Group will be engaged to help identify the implications for clinicians and understand their views about delivery. They will also be asked to help bring more clinicians into the work of the work stream.

Specific consideration will also be given to how to best influence the wider development of digital services where central government and arm's length bodies do not have direct levers e.g. through Care Quality Commission requirements and through influencing advisory networks (e.g. Association of Directors of Adult Social Services Informatics Network), transparency etc.

GOVERNANCE

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 1.1. Members will include representatives of the following:

- National Institute for Health and Care Excellence
- Health and Social Care Information Centre
- Care Quality Commission
- Public Health England
- NHS Blood & Transplant
- Clinical Reference Group
- Independent NIB member

The programme board will be co-chaired by Simon Stevens, Chief Executive of NHS England and Jon Rouse, Director General of Social Care, Local Government and Care Partnerships at the Department of Health.

The work stream will be led by Beverley Bryant, Director of Strategic Systems and Technology at NHS England, Charlotte Buckley, Deputy Director of People, Communities and Local Government at the Department of Health and James Hawkins, Director of Programmes Delivery at the Health and Social Care Information Centre.

HIGH LEVEL CHALLENGES AND RISKS

There is a critical need for this work stream to be underpinned by deep insight about the needs and views of patients, carers and citizens which is being addressed through the insight work which is capitalising on existing insight and commissioning additional insight work.

There is a need to ensure that the digital opportunity is inclusive, this will be tested through the design phase of this work stream and through developing proof of concepts to test the proposition.

The development of the citizen identity programme will be complex and views are being sought through an early engagement event.

A register of detailed project risks is being managed by the work stream programme office.

DECISIONS REQUIRED OF THE LEADERSHIP GROUP

Work stream 1.1 requests the leadership group make the following decisions:

- 1. Ratify the plans set out in this paper**