

Paper Ref: NIB 0403-007

BOARD PAPER – National Information Board Leadership Meeting

MARCH 2015

Title: Work stream 2.2:

Giving the right people access to the health and care data they need:
A Roadmap for comprehensive data on outcomes and value of service now –
ensuring the business intelligence requirements of health and care are met

Purpose of paper:

- To outline the objectives and plans of the work stream

Actions required by the Leadership Group:

- To note the report
- Agree that work stream 2.2 will provide oversight of the delivery of the proposed commitments outlined in this paper, as reflected in the NIB framework¹
- **Agree that work stream 2.2 will deliver the plan for the core secondary uses dataset development, rather than the production of the dataset itself** in relation to the NIB framework proposal^{1 2}
- To ratify the plans set out in this paper.

¹ The scope of the proposed NIB framework commitment objectives are detailed on p34 to 35 of the 'NIB Framework for Action: Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for patients and Citizens'

² The NIB will agree a core 'secondary uses' dataset that all NHS-funded care providers have to make available to support commissioning, regulation and transparency. The dataset will be reviewed regularly and developed in line with general and specific confidentiality requirements, for example those applicable to fertility treatments as regulated by the Human Fertilisation and Embryo Authority (HFEA)

CONTEXT AND OBJECTIVES

1. The purpose of the work stream is to give the right people access to all the health and care data they need beyond direct care. The work stream will develop a roadmap for comprehensive data on the quality, efficiency, and equity of health and care services and provide oversight of the full set of commitments outlined on pages 34-35 of the Framework:
2. By June 2015, the National Information Board (NIB) will agree a core 'secondary uses' dataset that all NHS-funded care providers have to make available to support commissioning, regulation and transparency. The dataset will be reviewed regularly and developed in line with general and specific confidentiality requirements, for example those applicable to fertility treatments as regulated by the Human Fertilisation and Embryo Authority (HFEA).
3. The NIB will, as part of that initiative, consult with care providers in social, domiciliary and residential care on the development and publication of appropriate datasets, to provide an effective insight into the safety and quality of their services.
4. Subject to ongoing evaluation, and with full safeguards, the care.data programme to link hospital and GP data will be extended nationally to other care settings to enable safe data-sharing for better analysis of care outcomes.
5. NHS England and Monitor will develop data standards to support new costing, pricing and payment systems to incentivise new models of care to deliver best outcomes and value for patients.
6. The NIB with clinical leaders will review how best to improve coverage and quality of clinical audits in all care contexts, and Public Health England (PHE) will establish a single comprehensive national rare disease registration service that collects and quality-assures data on all rare diseases across the whole population.
7. The Department of Health (DH) will publish, by December 2015, proposals to ensure that all central data requirements will be collected once, and that, in future, the vast majority of all central requirements will be through extractions at source.
8. The Health and Social Care Information Centre (HSCIC) will work with National Institute for Health and Care Excellence (NICE) to create a new Indicator Library service, which provides access to all the quality-assured nationally agreed indicators, and details the statistical methods that are used to construct them.
9. By 1 April 2015 the HSCIC will publish for consultation its proposals to deliver an enhanced suite of data services, which could provide a core element for the collection and sharing of data and records at the national level.

10. The HSCIC, the Care Quality Commission (CQC), Monitor and NHS Trust Development Authority (NHS TDA) will publish by October 2015 data quality standards for all NHS care providers, including the progressive improvement in the timeliness accuracy and completeness with which data is entered into electronic records and made accessible to carers and patients. The CQC will from April 2016 take performance against these data quality standards into consideration, as part of its regulatory regime.
11. NHS England will lead on a new Insight Strategy, to be published by April 2015, which will set out proposals for making better use of patient outcome and experience data, including Friends and Family Test, public surveys, Patient Reported Outcome Measures (PROMs) and related measures, social media analysis, online ratings and feedback.
12. NHS England will work with providers and patient groups to launch new experiments during 2015 to develop patient-centred outcome measures in specialised services and in maternity, and test the potential for their use in reimbursement for services, giving patients a role in determining how much a provider is paid based, in part, on their view of the outcome.

WORK PLAN

13. The contents of the roadmap will be developed in three phases: Discovery, Assessment, and Roadmap.

Phase 1: Discovery – current state:

14. Map the current data resources across health and care relating to secondary uses data
15. Map the current initiatives underway to improve secondary uses data across health and care.

Phase 2: Assessment – opportunities and challenges:

16. Assess the strengths and weaknesses, gaps and duplications of the data resources and initiatives identified in Phase 1
17. Agree and articulate the vision for secondary uses data for health and care.

Phase 3: Roadmap – plan of action:

18. Propose a more rational, harmonised set of initiatives to improve secondary uses data
19. Propose a roadmap for the order and implementation options to counter the weakness, gaps and duplications identified in Phase 2 that will be used to

inform existing programmes of work and to be the basis for commissioning new programmes of work.

GOVERNANCE

20. 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 the work stream. Members will include representatives of the following:

- Medicines and Healthcare Products Regulatory Authority
- Monitor
- NHS Business Services Authority
- Health and Social Care Information Centre
- Department of Health
- Independent NIB member
- Clinical Reference Group

21. The programme board is co-chaired by David Behan, Chief Executive of the Care Quality Commission and Simon Stevens, Chief Executive of NHS England.

22. The work stream is led by Emma Rourke, Director of Intelligence at the Care Quality Commission, Dr Geraint Lewis, Chief Data Officer at NHS England and Peter Sinden, Chief Information Officer at Monitor.

23. An assurance process will be established to ensure that the work stream board has appropriate oversight of the Framework commitments it is overseeing.

HIGH LEVEL CHALLENGES

24. Understanding the needs and views of a wide range of users (patients and carers, care professionals, commissioning, regulation, research, public health), getting their views on the proposed vision and building confidence and understanding of the way forward will be challenging given the breadth of stakeholders and complexity of the issues. An advisory panel is being established to represent user views and engagement events are being designed supported by a clear explanation of the purpose and value of the work.

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

DECISIONS REQUIRED OF THE LEADERSHIP GROUP

26. Work stream 2.2 requests the Leadership Group make the following decisions:

Agree that work stream 2.2 it will provide oversight of the delivery of the proposed commitments outlined in this paper, as reflected in the NIB framework³

Agree that work stream 2.2 will deliver the plan for the core secondary uses dataset development, rather than the production of the dataset itself in relation NIB framework proposal 1⁴

Ratify the plans set out in this paper.

³ The scope of the proposed NIB framework commitment objectives are detailed on p34 to 35 of the 'NIB Framework for Action: Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for patients and Citizens'

⁴ The NIB will agree a core 'secondary uses' dataset that all NHS-funded care providers have to make available to support commissioning, regulation and transparency. The dataset will be reviewed regularly and developed in line with general and specific confidentiality requirements, for example those applicable to fertility treatments as regulated by the Human Fertilisation and Embryo Authority (HFEA)