Programme Update: care.data

Eve Roodhouse

25 November 2013

Contents

Background

On 29 August 2013 the Board considered the draft legal directions received from NHS England in relation to the collection of primary care data. The planned extraction of data from GP Practice information systems and linkage to Hospital Episode Statistics (HES) is the first requirement for new data within the care.data programme.

At subsequent Board meetings the programme has been discussed and a regular update to the Board was requested. This paper reflects the first of these.

The importance of the programme and the need for regular updates has also been emphasised by the recent publication of the 'Bureaucracy and Regulatory Review' by the NHS Confederation in response to Robert Francis QC's report into failings in care at Mid Staffordshire NHS Foundation Trust and the 'Reducing unnecessary burdens concordat' asking the Department of Health and its Arm's Length Bodies to, amongst other things, work through the HSCIC as the national base for all data.

What is care.data?

The health and care system is experiencing a thirst for data and information like never before. The demand is for increased data and information about what and how care is delivered across care pathways and geographies rather than in individual care settings. This demand is coming from regulators, commissioners, providers, researchers, life sciences and the public alike.

The care.data programme will enable the HSCIC to make the necessary step change to respond to this demand by increasing the breadth of data which is collected, linked and disseminated whilst protecting personal confidential data and reducing burden on the system.

NHS England is the lead commissioning organisation on behalf of the Informatics Services Commissioning Group (ISCG).

Programme Status

The HSCIC appointed a Programme Director (Eve Roodhouse) in October 2013. The current focus is on ensuring that the programme has a solid foundation and the delivery of the primary-secondary care linked data.

To firmly establish the programme, the following key documentation has been developed:

- Programme Brief. The Programme Brief is in the review stage and will be considered by the HSCIC Portfolio Board in December. The Programme Definition Document will follow.

- Business case for the programme (the Strategic Outline Case or SOC). The SOC is currently in the approvals phase. The SOC includes the investment necessary to deliver a significant increase in the number and breadth of datasets collected, processed (including linkage) and disseminated (as set out in the care.data vision) and for an uplift in the capability of the HSCIC (in terms of IT infrastructure, software tools and information services) in order to securely, efficiently and effectively support the planned increase. The resulting 'strategic capability platform' will underpin the development of other services the HSCIC provides as well as care.data.

- Risk Potential Assessment (RPA). An RPA has been carried out and will shortly be submitted to the Major Projects Authority (MPA). This will trigger discussions regarding a Programme Validation Review (PVR) which will take place in New Year.

The preparations for the planned extraction of primary care data are well underway:

- In response to comments received from the Board in August, a phased rollout is being readied over a 3 month period with full extractions anticipated in May 2014 (first extraction from March) allowing time for the HSCIC to assess the quality of the data and the linkage before it is made available to commissioners in anonymised form. In addition, the Board's feedback on the data controller position is being picked up in discussion with the Information Commissioner's Office.

- Public awareness activity continues with a national leaflet drop to all households in England planned for January. A patient information line to handle patient queries in relation to the leaflet it currently being put in place. Digital content will be refreshed and updated in advance of the leaflet drop and complementary regional activity is planned by NHS England.

Work is progressing well in relation to a number of other data sets and data linkage.

- Productive discussions in relation to the Maternity and Children's Data Set (MCDS) in recent weeks are allowing the HSCIC to now plan with confidence.

- Initial discussions have taken place with NHS England, Public Health England and the Department of Health with regards the necessary legal Directions for the HSCIC to collect pathology results data.

- Linked data sets continue to be made available, with the next planned new routine linkage being Accident and Emergency Data (A&E) to Admitted Patient Care (APC).

Risks and Issues

Ref	Type	Description	Mitigation
1	Risk	Potential lack of clinical engagement (support for programme from clinicians) or confidence in what is being delivered.	Following feedback from doctors and the public the decision was taken to carry out a national leaflet drop in January 2014, allowing more time for GP practices to carry out fair processing activities. Complementary public awareness activities continue (see above). The BMA and the RCGP are also involved. Regular meetings are in place with the ICO, which are attended by NHS England and a representative from HSCIC Information Governance (Clare Sanderson). The Programme Director will attend future meetings. A comprehensive stakeholder engagement strategy and plan will be developed as part of Programme

Ref	Type	Description	Mitigation
			Definition.
2	Risk	Care.data primary care extract may not deliver on time due to the unknown amount and complexity of defects that may occur during certification and first of type activities based on progress to date.	Working with each supplier to apply the lessons learnt from previous incidents and testing phases. All future activities have been planned and external resources/governance bodies have been lined up to speed up the approval processes. Daily calls are in place with suppliers. Where defects do occur the resolution is shared with other suppliers who are yet to complete that stage to prevent GPET-E inadvertently repeating the same error. Working through engagement areas to ensure appropriate public awareness supports the infrastructure.
3	Risk	Proposed reduction of charges for data to £1 put forward by NHS England not agreed.	Whilst legal advice indicates the effective removal of charges may be possible, there remains a need to clarify principles with NHS England in terms of where charges would be reduced. It is also proposed that this should be discussed at the Informatics Services Commissioning Group (ISCG) to ensure that any wider implications can be understood. Discussions are underway with NHS England to agree a way forward.
4	Issue	The implementation of the Maternity and Children's data set (MCDS) has been delayed due to transfer of sponsorship from the Department of Health to NHS England.	MCDS includes three datasets: Maternity; Child Health; and, Child and Adolescent Mental Health. NHS England as the new sponsor for the MCDS project required a degree of due diligence be completed before the necessary funding be committed. This included a more detailed gap analysis/review of the maternity data set in particular. Due diligence is now complete, with

Ref	Type	Description	Mitigation
			the outcome that the datasets will be implemented as planned (albeit delayed). Revised plans and financial forecast are being prepared.
5	Risk	The programme team is working at risk in some areas without an approved business case and funding stream.	As reported above the SOC has been developed and is going through review and approvals. The costs of HSCIC activity relating to the primary-secondary care linkage are being met by funding put aside to support HSCIC Data Linkage Programme in FY13/14 and other areas of underspend.
6	Risk	The funding source(s) for the programme going forwards is not yet confirmed.	With the SOC progressing through the approvals process we can now begin to progress discussions on the appropriate funding source(s) for the programme.

Actions Required of the Board

The status update is provided for information and for comment.