Programme Update: care.data

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1. Background

On 29 August 2013 the HSCIC 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.

What is care.data?

The NHS has some of the best information systems in the world. Since the 1980s, we have been collecting information about every hospital admission, nationwide. This information is brought together at the Health and Social Care Information Centre, where it is anonymised. The information has been invaluable for monitoring the quality of hospital care, for planning NHS services, and for conducting research into new treatments. Whilst we have this type of information for some care provided outside hospitals, there are significant gaps meaning that it is not possible to see a complete picture of the care that individuals receive.

NHS England has therefore commissioned a programme on behalf of the NHS, public health and social care services to address these gaps. Known as the care.data programme, this initiative will ensure that there is more rounded information available to citizens, patients, clinicians, researchers and the people that plan health and care services. Our aim is to ensure that the best possible evidence is available to improve the quality of care for all.

2. Programme Status

Delivery of the primary-secondary care linked dataset

On 18th February 2014 NHS England made the decision to extend the care.data public awareness campaign until the autumn, allowing the public more time to learn about information sharing before the planned extraction of primary care data. NHS England committed to:

- Working with patients and professional groups (including the British Medical Association, the Royal College of GPs and Healthwatch) to develop additional practical steps to promote awareness with patients and the public, and ensure information is accessible and reaches all sections of the community, including people with disabilities;

- Looking into further measures that could be taken to build public confidence, in particular steps relating to scrutiny of ways in which the information will be used to benefit NHS patients; and,

- Delay the planned extraction of data from GP systems until the autumn.

Dr. Dan Poulter (Parliamentary Under Secretary of State), Tim Kelsey (National Director for Patients and Information, NHS England) and Max Jones (Director of Data and Information Services, HSCIC) also attended the Health Select Committee on 25th February 2014 to take questions on care.data.

Since February the programme team has worked closely with NHS England to:

- **Strengthen programme governance.** Specifically, Tim Kelsey has taken on the role of Senior Responsible Owner (SRO) in the short term (subject to confirmation by the Programme Board on 31st March 2014). Eve Roodhouse has also been confirmed as overall Programme Director. Weekly SRO Accountability meetings have been established and an Advisory Group has been set up to provide independent advice to the programme. The group will be independent of both NHS England and the HSCIC and will be chaired by Ciaran Devane (Chief Executive, Macmillan Cancer Support) and include representatives from professional and citizen groups including the British Medical Association, Healthwatch, the Association of Medical Research Charities, the British Heart Foundation, Big Brother Watch and MedConfidential.

- **Establish the necessary activities to promote awareness and support for the planned extraction of primary care data.** A six month extension workstream has been established. Led by Ronan O'Connor (NHS England) this workstream will, following a period of listening, set out the steps that must be taken and the associated dependencies before data can be extracted and/or disseminated. This is expected to include (but will not be limited to): the provision of additional guidance and materials to General Practice and an increased awareness amongst GPs of the programme; the publication of the code of practice for confidentiality by the HSCIC; and, legislative changes set out by the Department of Health (see SofS Measures paper) having become statute.

- **Re-plan data extraction.** The approach to data collection has not changed, in that a phased rollout is being readied over a 3 month period 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. Analysts from the HSCIC will collaborate with NHS England Analytics to carry out early analysis of the anonymised linked data onsite at the HSCIC and the scope for this early analysis has been agreed although logistics are now being reconfirmed following the extension to the public awareness campaign.

- **Progress plans for phase one of the strategic capability platform.** A project has been established to deliver an enhanced technical platform on which to land and process the primary care data to ensure that the public and the HSCIC has confidence in the security of the data. This will be a stepping stone towards the target strategic capability platform, (see business case update below).

NHS England and the HSCIC have also worked together to extend the patient information line until the autumn and to ensure that the HSCIC contact centre is in a position to continue to provide the GP information line.

Programme Definition

In parallel, work continues to ensure that the programme has a solid foundation.

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

- **Programme Brief and Definition Documents.** The programme brief was approved by the Programme Board on 28th January 2014. The Programme Definition Documents are now in production, although completion during April will depend on the successful recruitment of additional programme controls staff to the team.

- **Business case for the programme (the Strategic Outline Case or SOC).** Limited progress has been made on the development of the SOC due to resources being diverted to support urgent activities during Q4 FY13/14. The programme team now intends to progress a Professional Services Business Case to secure additional resources to ensure that the SOC can be delivered in Q1 FY14/15. This will be alongside recruitment to key posts in the team. 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. The SOC will be made available to the HSCIC Board as part of the next review cycle.

- **Project Validation Review (PVR).** Following the submission of a Risk Potential Assessment (RPA) to the Major Projects Authority (MPA) a PVR is being planned for the end of April 2014. The review will take the form of a facilitated discussion and will trigger the programme's entry to the Government Major Projects Portfolio (GMPP). The PVR has been jointly commissioned by Tim Kelsey (as SRO) and Karen Wheeler (as Accountable Officer).

Risks and Issues

Ref	Type	Description	Mitigation
a	Risk	Potential lack of clinical engagement (support for programme from clinicians) or confidence in what is being delivered.	See updates above.
b	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.	This risk is now much reduced due to the extension to the public awareness campaign. The delivery of primary-secondary care linked data is dependent on the successful delivery of GPES, with limited contingency. A programme manager continues to work closely with the GPES team to build confidence in delivery and to strengthen mitigation actions.
c	Risk	The programme team is working at risk in some areas without an approved business case and funding stream.	As reported above additional resource is being sought to ensure that the SOC can be progressed through the review and approvals process in Q1 FY14/15. The costs of HSCIC activity relating to the

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			primary-secondary care linkage to date has been met by funding put aside to support HSCIC Data Linkage Programme in FY13/14 and other areas of underspend.
d	Risk	The funding source(s) for the programme going forwards is not yet confirmed.	Despite limited progress in recent weeks the SOC is sufficiently mature that we can now begin to progress discussions on the appropriate funding source(s) for the programme.
e	Risk (New)	Unless the controls around data release are fully transparent there is a risk that healthcare professionals and the public will not support the programme.	The HSCIC will publish a report detailing all data released under the HSCIC on April 2/3, including the legal basis on which data was released and the purpose to which the data is being put. This report will be updated on a quarterly basis and is intended to encourage public scrutiny of HSCIC decisions.
			Sir Nick Partridge, has agreed to conduct an audit of all the data releases made by the predecessor organisation, NHS Information Centre, and report on this to the HSCIC Board by the end of April;
			SofS brought forward amendments to the Care Bill intended to increase public confidence (see separate Board paper).
			The HSCIC has established a Transparency and Information Assurance Programme which will be responsible for ensuring the effective implementation of changes resulting from SofS measures within the HSCIC.
			The programme team is working with HSCIC colleagues, NHS England and departmental colleagues to develop a straightforward overview of the target governance for communication purposes which will be tested with the care.data advisory group.

Ref	Type	Description	Mitigation
f	Issue (New)	The programme team has insufficient resources to complete the programme definition <u>and</u> to support the delivery of the primary-secondary care linked dataset in the next three months.	Key posts will shortly be advertised. In addition, Professional Services Business Cases (PSBCs) will be used to ensure adequate support is in place for communications activity and to develop the Strategic Outline Case (see above). Additional resource is also being sought from Portfolio Delivery.

3. Actions Required of the Board

The status update is provided for information and for comment.