

Programme Update: care.data

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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. This paper reflects the second of these.

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.

Programme Status

The current focus continues to be 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 was considered by the HSCIC Portfolio Board in December, resulting in the inclusion of the programme on the HSCIC portfolio. The programme brief will be put forward for approval by the care.data Programme Board on 28 January. The Programme Definition Document will follow.
- Business case for the programme (the Strategic Outline Case or SOC). As reported in December 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. The SOC will be made available to the HSCIC Board following review and approval by the care.data Programme Board and the Informatics Services Commissioning Group (ISCG), important governance steps in ensuring the support of the Department of Health and the Arm's Length Bodies.

- Project Validation Review (PVR). Following the submission of a Risk Potential Assessment (RPA) to the Major Projects Authority (MPA) a PVR is being planned. 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 preparations for the planned extraction of primary care data are well underway:

- Directions from NHS England for the collection and analysis of primary care data have been formally received (and acknowledged) by the HSCIC. The Directions will be published online by NHS England and the HSCIC website will link to this as soon as it is available.
- As reported in December, 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. 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.
- An application will be considered by the GPES Independent Advisory Group in February to agree the details of a data extract which will support the HSCIC to apply the objection codes.
- Work is progressing to develop a dedicated environment in which to store and process the primary-secondary care linked dataset. This will be the forerunner to the strategic capability platform.
- Public awareness activity continues. The national leaflet drop to all households in England began on 6 January as planned and will conclude on 31 January. The patient information line to handle patient queries in relation to the leaflet is operational and has handled nearly 3500 calls up to 23 January inclusive. The top queries are:
 1. Can I change my mind?
 2. I can't get to my GP Practice to object what should I do?
 3. How long have I got to decide if I want to object?
 4. Do I need to do anything if I'm happy for my information to be used?
 5. What is the secure environment mentioned in the leaflet?
- Digital content was refreshed and updated in advance of the leaflet drop. The HSCIC web page about 'how we look after information' has had 4040 unique visits between 6 January and 23 January inclusive. A short animation has been produced and made available to download so that practices can include it on their websites.
- The programme team has been working closely with the communications team to respond to media queries and FOIs received. Several TV and radio interviews have been given.

Work is progressing well in relation to a number of other areas.

- Following market engagement in autumn 2013 a procurement evaluation will get underway in late January to identify an Enterprise Wide De-Identification Solution. This is required to standardise the approach to de-identifying patient data across the HSCIC enterprise in order to meet increased demand for extracts from a greater

number of data assets. The solution will ensure that any patient confidential information leaving the HSCIC continues to be appropriately treated; minimising the risk of unauthorised patient identification whilst preserving the analytical value of extracts.

- The delivery plan for the Maternity and Children’s Data Set (MCDS) has now been approved and work has commenced with provider units in Maternity and Child Health to pilot data collections.
- 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

There are no new risks or issues raised in this report.

Ref	Type	Description	Mitigation
a	Risk	Potential lack of clinical engagement (support for programme from clinicians) or confidence in what is being delivered.	<p>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. The BMA and the RCGP are also involved.</p> <p>Regular meetings are in place with the ICO, which are attended by NHS England, the HSCIC Programme Director and a representative from HSCIC Information Governance.</p> <p>A comprehensive stakeholder engagement strategy and plan will be developed as part of Programme Definition.</p>
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.	The delivery of primary-secondary care linked data is dependent on the successful delivery of GPES, with limited contingency. A programme manager has been working very closely with the GPES team to build confidence in delivery and to strengthen mitigation actions.
c	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

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			<p>Informatics Services Commissioning Group (ISCG) to ensure that any wider implications can be understood.</p> <p>The Department of Health has provided guidance to confirm that the current approach (cost recovery) is in line with government policy.</p> <p>Discussions are underway with NHS England to agree a way forward.</p>
d	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.
e	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.