

# Programme Update: care.data

**Eve Roodhouse**

**02 May 2014**

# Contents

---

<b>Contents</b>	<b>2</b>
<b>1. Background</b>	<b>3</b>
What is care.data?	3
<b>2. Programme Status</b>	<b>3</b>
Delivery of the primary-secondary care linked dataset	3
Programme Definition	4
Risks and Issues	5
<b>3. Actions Required of the Board</b>	<b>7</b>

---

## 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

Following from the NHS England decision in February to extend the care.data public awareness campaign until the autumn, thus allowing the public more time to learn about information sharing before the planned extraction of primary care data, a large amount of positive activity has taken place, the approach and outline of which has been reported to the Secretary of State :

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

- **Establish the revised programme governance.** Tim Kelsey was formally appointed as Senior Responsible Owner (SRO) by the Programme Board on 31<sup>st</sup> March 2014 (Eve Roodhouse is the overall Programme Director). The Terms of Reference and membership of the Programme Board are being reviewed and it will meet at least every 6 weeks from now. Weekly SRO Accountability meetings take place to provide accountability for all workstream delivery and these are supported by a number of management reporting products. The Advisory Group, set up to provide independent advice to the programme and chaired by Ciaran Devane (Chief Executive, Macmillan Cancer Support), has now met twice (third meeting scheduled for 2<sup>nd</sup> May) and is working very well.
- **Establish the necessary activities to promote awareness and support for the planned extraction of primary care data.** The NHS England-led six month

extension and communications and stakeholder engagement workstreams are now supported by a plan that sets out the approach to engagement and includes a large number of regional awareness events across the country through the extension period. This plan is being discussed with the Advisory Group and will be supported by a communications pack that includes: a cover note for regional colleagues; a care.data factsheet; key core messages; a benefits paper; a case studies paper; and FAQs. In relation to this, a business case to enable research activity has been approved.

- **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 having become statute (there is now a timetable in place for this legislation and this has been discussed with the Advisory Group). Additionally, policy workshops are being held to address supporting requirements (e.g. secure data laboratory, objections process). It is expected that these will be formalised and communicated by the end of May.
- **Re-plan data extraction.** It has already been announced that the first extractions of primary care data will now involve a number of pilot practices (between 100 and 500) and the programme team is currently working to agree how those pilot practices will be selected and engaged in the process. It remains the case that during this first phase only HSCIC and NHS England Analytics teams will have access to the anonymised data in a controlled environment on HSCIC property.
- 

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/is in development:

- **Programme Brief and Definition Documents.** The programme brief was approved by the Programme Board previously and the Programme Definition Document is now in production, and will detail the objectives and scope across the workstreams. Completion of this 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).** As was reported previously, limited progress has been made on the development of the SOC (since its first iteration in December 2013) due to resources being diverted to support urgent activities during Q4 FY13/14. The programme team is now progressing a Professional Services Business Case to secure additional resources to ensure that the SOC can be delivered as soon as possible in Q1 FY14/15. 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.

- **Enhanced plans and risk register.** Cross-programme plans, risk management and highlight reports covering delivery activity being led by the HSCIC and NHS England are now in place in support of SRO Accountability requirements. Work continues to ensure these processes are firmly embedded and working effectively across the two organisations.

## Assurance

- **Project Validation Review (PVR).** The Major Projects Authority (MPA) has just completed (week commencing 28<sup>th</sup> April) a PVR for the programme. A PVR forms the first assurance stage and the delivery confidence assessment resulting from it supports approval of the business case. The SRO and Programme Director have met with the review team to discuss initial findings, with the final report due to be delivered to the SRO week commencing 6<sup>th</sup> May. The PVR was jointly commissioned by Tim Kelsey (as SRO) and Karen Wheeler (as Accountable Officer) and, to note, PVRs are treated as confidential (under section 33 of the Data Protection Act).

## Resources

- **Recruitment of resources to support delivery.** The Programme Director is currently recruiting to key posts in her team (interviews early May) and recruitment for other key roles is being progressed.

## 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 – communications plan and stakeholder engagement strategy with regional events
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.

Ref	Type	Description	Mitigation
c	Issue	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.
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.	<p>The HSCIC published a report detailing all data released under the HSCIC in April, 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.</p> <p>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 in the next period.</p> <p>SofS brought forward amendments to the Care Bill intended to increase public confidence (see separate Board paper).</p> <p>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.</p> <p>The programme team has worked with HSCIC colleagues, NHS England and departmental colleagues to develop a straightforward overview of the target governance for communication purposes and this was presented to the Advisory Group in mid April.</p>

Ref	Type	Description	Mitigation
f	Issue	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.	Key posts are now being recruited to. In addition, work is underway to ensure adequate support is in place to develop the Strategic Outline Case (see above). Additional resource is also being sought from the HSCIC Portfolio Delivery team.

### 3.Actions Required of the Board

*The status update is provided for information and for comment.*