care.data Programme Board (and ISCG sub-group)

Monday 28th January 2014
14.00 – 16.30
VC: Quarry House, Leeds; Skipton House, London

MINUTES

Present:

Christine Outram (Chair)	Director of Strategy & Intelligence, NHS England, and care.data SRO
Dr Geraint Lewis	Chief Data Officer, NHS England
Peter Flynn	Head of Strategic Intelligence, NHS England
Richard Murray	Chief Analyst, NHS England
Eve Roodhouse	Programme Director Health & Social Care Information Centre (HSCIC)
Neil Stutchbury	Monitor
Iain Wallen	Director of Information and Analytics, NHS Trust Development Authority
Peter Hall	External Relations Directorate, Department of Health (DH)
Chris Carrigan	Public Health England
Ming Tang	Director, Data and Information Management Systems, NHS England
Dr Martin Bardsley	Head of Research, Nuffield Trust
Tom Ward	Care Quality Commission
Peter Knight	Deputy Director, Head of Research Information and Intelligence, Research & Development Directorate, DH
Dr Jeremy Veillard	Vice-President, Research and Analysis, Canadian Institute for Health Information, University of Toronto (dialled-in)
Dr Pete Green	NHS Medway (CCG representative)
Jeremy Thorp	Director of Business Architecture, HSCIC
John Parkinson	Clinical Practice Research Datalink (CPRD)
Phil Walker	External Relations Directorate, DH
Alex Porter	Clinical Informatics, NHS England
David Davis	Clinical Informatics, NHS England (dialled-in)
Gill Sayers	Programme Support, HSCIC (and board support)
David Farrell	Programme Manager, HSCIC (and scribe)

Apologies:

Alistair McDonald	NHS Business Services Authority
Martin Campbell	NHS England, SRO for the National Tariff System (NTS) programme
Martin Hall	Health Education England
Max Jones	Director of Information and Data Services, HSCIC
Dr Mark Davies	Executive Medical Director, HSCIC
Alexia Tonnel	NICE
Prof John Newton	Chief Knowledge Officer Designate, Public Health England (Chris Carrigan deputised)
Mike Foster	Deputy Chief Executive, University College Hospital London
Dr Jonathan Kay	Director of Clinical Informatics, NHS England (Alex Porter and David Davis deputised)
MCDS representative	Maternity and Children's programme (MCDS) representative (tbc)

A	Meeting Governance and Overview
1	Introductions and apologies

Christine Outram (CO) welcomed everyone to the meeting and noted apologies.

She explained that a change in Mike Foster's working role mean that he will not be able to give his time to the programme board going forward. Mike, as an external subject matter expert, has been a very active member of the care.data board and CO and the board would like to thank him for all his help and support.

NEW BOARD ACTION (45):
Board to consider an appropriate external subject matter expert replacement for Mike Foster. |
| 2 | Agenda overview and requests for AOB

CO explained the agenda structure and provided an overview of the agenda items.

The proposed European regulation for data confidentiality was agreed for inclusion in AOB. |
| 3 | Acceptance of minutes from previous meeting

The minutes from the board held on 25th November were submitted for acceptance.

Two queries were raised by Peter Knight (PK) in relation to the Delivery Report section of the minutes:

The first of these queries related to the minutes not specifically stating that Cabinet Office approval would be needed for the Strategic Outline Case (SOC).
In relation to this, the minutes were updated for clarity (this was done in advance of the January board papers submission) to reflect that Cabinet Office approval is indeed required for the SOC.

The second of PK's queries related to charging and was in two parts:

Firstly, he requested clarity of wording to reflect that the current policy position on 'data for £1' is not current policy (PK had checked this with Mark Davies at DH) and, as such the HMT Green Book states that all government ICT investments should be on a cost recovery basis and charges for the service to be sufficient to cover the initial capital investment and the on-going commitment to the subsequent revenue costs. Unless and until the policy changes the idea of data for a £1 is only an aspiration and would need formal approval.

In relation to this part, the programme board recognised and agreed with his comments.

Secondly, he raised some concern about the phrase in the minutes which stated: 'charging commercial companies more than charities'. His understanding is that in competition law you cannot differentiate charging by sector as this approach would be anti-competitive and subject to legal challenge. The only basis for differential charging would by the service level on offer.

In relation to this part, the programme board recognised and agreed with his comments and subsequent discussion also followed with a number of points made relating to this:
Geraint Lewis (GL) said that whilst there may be an ambition to reduce charges, this must be across the board (i.e. cannot differentiate between charities and others).
PK said that it should be clear that the HSCIC do not charge for data but charge for services to provide data.
It was agreed that there is still a need to discuss charging at the main ISCG as there are a number of charging policies across other areas too and these may impact/be impacted. |

	The remainder of the minutes were accepted and addendum notes have been added (to the minutes that were submitted for approval) as stated above to reflect the queries. The updated version of the minutes (with addendums) can be made available for board members by the HSCIC programme team.
4	ISCG update CO provided a brief update following on from the recent ISCG meeting. She explained that Karen Wheeler (from DH) has commissioned a review of governance arrangements for informatics programmes. Additionally, she explained that the intention is that the ISCG will be known as the National Information Board (NIB) and that this will seamlessly take over from the ISCG (i.e. Tim Kelsey will continue to chair in role as National Information Director). Formal introduction of this change is to follow. Board members also fed in their observations from the recent ISCG open-house event which, with a large number of stakeholders attending, was received very positively and had a strong engagement value.
B	**Delivery**
5	Board Highlight Report (delivery report) Addendum Note (1): Subsequent to the board meeting and following a very high profile response (media, public, clinical) in relation to the public awareness campaign, an announcement was made (on 18th February) by NHS England stating that the intention would now be to begin collecting data from GP surgeries in the autumn, instead of April, to allow more time to build the understanding of the benefits of using the information, what safeguards are in place, and how people can opt out if they choose to. Continued engagement with patients and professional groups – including the BMA, RCGP and Healthwatch – will take place to develop additional practical steps to promote awareness with patients and the public and to look at measures to build public confidence. Eve Roodhouse (ER) presented the board report, highlighting key points. She explained that there are two key areas of focus: 1) Ensuring a solid foundation for the programme (e.g. through the development and approval of the Programme Brief and business case) – indeed the Brief was submitted for this board's approval. She went on to explain that the programme now has a formal presence on the HSCIC portfolio and is now also subject to a formal (Major Projects Authority) assurance process. The first stage of this assurance, a project validation Review (PVR), is being scheduled to take place in March. The output from this PVR (delivery confidence assessment) will inform the endorsement of the SOC. 2) Delivery of the primary care data set. This was supported by the public awareness campaign (national leaflet drop) from early January. She explained that the intention is that a separate request is being made to the GPES Independent Advisory Group (IAG) as regards objections handling. The Maternity and Children's Data Set (MCDS) project was reported to be back on a firm footing (following the resolution of earlier scope and funding issues) with pilot collections from provider units are being prepared. It was noted however that progress in this area against the agreed plan is subject to the Memorandum of Understanding being in place between HSCIC and NHS England (this was awaiting signature at the time of the board). **EXISTING BOARD ACTION (38) CLOSED:** *Agreed to close as proposed (related to completion of gap review for MCDS – now completed).* In relation to resourcing for the HSCIC programme team, ER said that she is expecting to be able to recruit to the team (direct reports) in the next period.

Procurement of the enterprise-wide de-identification solution (EDS) was reported as progressing – this is to enable the 'next level/improved' corporate pseudonymisation for capability in the HSCIC.

The proposed approach for ensuring technical capability and capacity for handling the primary care extract has been developed and this is currently going through internal HSCIC approvals (phase 1 of the strategic platform).

CO picked out the public awareness campaign interest level as a specific area for further discussion:

GL provided some more background to the leaflet. He explained that the decision around leaflet logistics was driven by the academic literature (which suggests that unaddressed leaflets and individually addressed letters have similar effectiveness in terms of awareness raising), and cost (unaddressed leaflets are considerably cheaper). As regards the inclusion of an opt out form, there may be a need to revisit the objections process although he reiterated that decisions about handling objections are the responsibility of GPs as data controllers and that the decision not to include an opt-out form with the leaflet was agreed with the BMA and RCGP.

He also explained that media interest was high from the first day (6th January) of the campaign (it was the top news story on the BBC web site that day). A patient information line was in place to support this plus a line to deal with GP queries. Research charities and other charities also started a (independent) campaign around the same time as regards not opting out. Clarity had also been received from the Information Commissioners Office (ICO) as regards fair processing and this had been issued via a blog (ICO blog). CO added that the Information Commissioner had appeared on BBC Breakfast TV with positive messages around alignment with his advice which was reassuring.

Pete Green (PG) said his view, as a GP, is that GPs wanted to be sure they were acting properly and that understanding and communicating the benefits of good information is the key for patients. Similar to the Summary Care Records programme, it should be expected that there will always be some people who choose to opt out. He suggested that it may be useful for the BMA to issue a guidance/template to ensure GPs are sending out the correct, consistent message.

PK explained that the recent feedback he had picked up (including from the House of Lords) was broadly supportive however two points were raised as regards the type of leaflet/delivery method (non-personalised so seen by some as accompanying the 'junk' mail) and also as to why no box to opt out was included. GL explained that the decision around leaflet type was driven by cost but also by the need to ensure the coverage that general mail brings. As regards the inclusion of an opt out box, there may be a need to revisit through the objections process although he reiterated that this approach (i.e. the leaflet as it went out) was agreed with the BMA and RCGP.

Martin Bardsley (MB) asked specifically about the patient information line and how effective this has been. GL explained that it had dealt with roughly 1000 queries per week which is quite a low number in relation to 22.5 million leaflets being sent out (although this is also supported by well-developed FAQs via the web site) and ER also stated the 5 most common patient questions that had been received.

Addendum Note (2):
Patient information line calls handled (6-week period from 6th Jan):

	Wk1	Wk2	Wk3	Wk4	Wk5	Wk6	Total
Calls handled	740	1288	1842	2543	1478	1297	9188

Top patient FAQs (through the 6-week period from 6th Jan):
1. Can I change my mind?

2. How long have I got to decide if I want to object?
3. Can I prevent data from other healthcare settings flowing to the HSCIC?
4. I can't get into my GP practice to object what should I do?

GP calls handled (6-week period from 6th Jan) by the HSCIC contact centre:

	Wk1	Wk2	Wk3	Wk4	Wk5	Wk6	Total
Calls handled	49	127	121	172	117	118	704

Top 3 GP queries (through the 6-week period from 6th Jan):
1. Can I have care.data posters/leaflets?
2. What read codes do I use for patients who wish to object?
3. Is there an opt out form/objection form?

Web stats (page hits) for the main (HSCIC) patient information page (6-week period from 6th Jan):

Web Page	Wk1	Wk2	Wk3	Wk4	Wk5	Wk6	Total
Looking after your health and care information	1187	1477	1913	2543	2573	2439	12132
Why information is needed	203	322	321	405	340	349	1940
Rules for sharing information	303	461	517	827	807	738	3653

Phil Walker (PW) asked whether communications are being co-ordinated across the HSCIC, DH and NHS England and GL confirmed that the three organisations are now aligned and working very closely with consistent messages. GL also invited board members from other organisations to speak with him separately around how their own communications areas could align if they thought this to be appropriate/needed.

EXISTING BOARD ACTION (41) CLOSED:
Link up of NHS England, HSCIC, DH and Public Health England communications areas confirmed; agreed to close outstanding action.

In response to a question from PK as regards the GP IAG submissions and levels of scrutiny for the programme, ER explained that the programme team are working with Information Governance in HSCIC as regards a clear corporate policy for levels of scrutiny for, for example, pseudonymised data, how scrutiny should be applied and which groups should be involved in what way (e.g. GPES IAG involvement). This will be reported back to the programme board at a later date.

Finally, ER talked briefly through each of the key risks highlighted on the board report.

EXISTING BOARD ACTION (23) UPDATED:
Stakeholder engagement actions are now in 2-part:
- *A stakeholder engagement strategy for the programme is in development and will be included with the Programme Definition Document (PDD) for consideration by the board*
- *A clear approach to stakeholder, patient and clinical engagement will be established as a result of the recent decision to extend the awareness campaign/consultation period and this too will be presented for the programme board*

6 | Delivery framework

ER explained that, in line with programme products required as part of the HSCIC delivery framework, the SOC is in development and the board will be updated as to next timelines (i.e. review and approval) in due course.

EXISTING BOARD ACTION (39) UPDATED:
SOC still in development and intention is still to seek endorsement/approval from the programme board however this will not be before the completion of the Project Validation Review (PVR) assurance step, which is currently being scheduled.

	Following approval of the Programme Brief (anticipated following this programme board) development of the Programme Definition Document will commence. She also informed the board that a Benefits Lead is now in place and, with workshops having taken place and being scheduled, is now working towards the definition and profiling of benefits for the programme. It is anticipated that the Benefits Strategy will be presented for the next board at the end of March. **EXISTING BOARD ACTION (32) UPDATED:** *Still the intention to present benefits strategy for programme board in March.*
7	<u>Programme Brief (for board acceptance)</u> The Programme Brief was submitted (with board papers) for board approval. ER explained that this had been approved by CO (as care.data SRO) in advance of submission for the HSCIC Portfolio Board and was an input for the approval of the programme onto the HSCIC work portfolio (formally approved onto portfolio on 18th December). At the request of the board members, the time for providing comments was extended for a further week after which, assuming there were only minor changes made, the finalised Programme Brief would be marked as Approved by Board and made available to board members upon request (from the HSCIC programme team), with the action closed. **EXISTING BOARD ACTION (40) CLOSED:** *Minor comments received following extended review period - Brief finalised and marked as Approved by Board, with the action closed.*
C	**Strategy**
8	<u>Strategic overview, including Hospital Dataset consultation</u> The areas that GL wanted to cover as regards the primary care data extract and the public awareness campaign were fully covered earlier (Delivery section) in the meeting. GL explained that he is drafting a Chief Data Officer Briefing in relation to care.data and information use and that this would be sent to all board members for their review. **NEW BOARD ACTION (46):** *CDO Briefing to be sent to all board members for their review.* Addendum Note (3): CDO Briefing paper was sent out for review on 20/02. He also explained that, following the hospital data set consultation, the proposed next steps were currently being documented and would be made available for programme board review. **EXISTING ACTION (10) UPDATED:** *Proposed next steps following hospital data set consultation are currently being documented and will be made available for programme board review when ready.*
9	<u>Data set prioritisation</u> Peter Flynn (PF) presented a paper ('Proposed approach for selecting which additional patient-level data sets should be added to phase 1 of the programme' - submitted with the board papers) that outlined an approach for prioritising which data sets should be included in which programme phase. He explained that this involves thinking beyond where we are now and that it involves working with each organisation to understand their data set requirements. The intention is then to try and map the data sets against the (prioritisation) matrix (in the approach) to help decide priority within the phased structure of the programme. The paper identifies a

number of data sets that could be incorporated, with differing current states and with differing complexity related to them.

PF also talked about the potential to introduce accelerator projects to support this prioritisation exercise and to help the requirements, and subsequently implementation, process.

Chris Carrigan (CC) said he thought it was a good paper and asked whether Hospital Episode Statistics (HES) would be at the centre of linkage. ER explained that the new index tool (EDS, see also delivery report above) will drive the linkage so HES won't need to be at centre.

As regards the thinking behind the numbers of data sets that can be included in each phase, ER explained the context/background to the data sets and their inclusion through the work thus far on the development of the SOC. She explained that assumptions (particularly around infrastructure/time/effort/cost) currently included around 15 data sets in each phase (assumed 2 year phases) of differing complexity so this would be then be re-impacted following the prioritisation exercise (e.g. the inclusion a higher proportion of complex data sets may mean that is not possible to include as many as 15 in the phase).

CC said that a number of the data sets mentioned in the paper had already been included for linkage (in Public Health England work) for cancer modelling and the programme needs to be aware that there at lots of lessons/examples/experiences in relation to some of these.

PK thought that data quality is a missing element for inclusion in this prioritisation approach. He felt it was important that the resource need to ensure appropriate data quality is considered both in here and in business case planning (this has been noted by the HSCIC programme team in relation to SOC development).

John Parkinson (JP) thought it important that, as a starting point, each of the candidate data sets for prioritisation should be defined very clearly.

Regarding specific data sets, PG thought it important to particularly include social care. ER said that the Community Data Set was ready to roll out but had no funding currently in place. Jeremy Thorp (JT) added to this, saying it has been approved for local use (through the Standards Board) but that we would like to get it approved for national use.

In response to a specific question around whether there are any constraints on data sets nationally, GL said it was important that we consider data sets at a national level but that demonstrators may be appropriate at a local level.

Ming Tang (MT) added that many of the data flows are captured locally and as part of the Data Services for Commissioners (DSC) programme we have flows taking place so this could help (and reduce burden for providers).

JT said that there are a number of applications currently coming through the standards process (dementia and health visitors data are examples) that could be considered for inclusion within this approach.

OUTCOME – The board approved the proposed approach as presented in the paper.

NEW BOARD ACTION (47):
Board to nominate people to support the prioritisation approach (to be led by Peter Flynn) – nominations to David Farrell – davidfarrell@nhs.net

10	Related strategy items

Strategy for Data on Quality

Tom Ward (TW) presented the CQC Strategy for Data on Quality (the slides for which have been sent to board members to accompany these minutes), talking through a number of key points: |

	- Prioritisation of data sets for measuring quality (inc performance) took place - ALBs were asked a number of questions regarding gaps and challenges including where are opportunities for quick improvements? - Mental Health, Community and Adult Social Care came out top of list (although there is no framework for Adult Social Care) - Key themes included patient pathway, lack of flow, completeness/quality - Next 4-6 weeks the team are looking at what are the things that can be done to drive forward against these priorities and to take these back to ISCG - Overriding message: data sets on quality are not separate – they sit on top of/complement **EXISTING ACTION (44) UPDATED:** *As regards CQC presenting the Strategy for Data on Quality for the board, this is now complete and the action closed.*
D	**Other Business**
11	Review of remaining open actions (i.e. a review of those actions from the Open Actions Log that were due for review and not addressed during by previous agenda items during the meeting) **EXISTING ACTION (12) CLOSED:** *As regards the Prospectus, board member comments were received and impacted however there is no plan to release further/next version at this time and the content will be used to inform the Programme Definition Document (PDD) and SOC. Agreed to close the action.* **EXISTING ACTION (29) UPDATED:** *As regards an earlier proposed development (John Parkinson) - 'Implantable Devices – adding a field to HES' - a paper (outline, work request) was submitted to the Standards for Care Information (SCCI) ('Standards ISCG sub-group') and the board were asked to suggest an approach to take this forward. It was agreed that Jeremy Thorp would pick up and establish how it can move forward as a request via the SCCI group.* **EXISTING ACTION (37) UPDATED:** *As regards patient representation on the board, Peter Flynn was chasing appropriate approach to representation with NHS England Patient and Public Voice (PPV) as a matter of priority. Chris Outram now agreed to pick up directly with Giles Wilmore.* **EXISTING ACTION (42) CLOSED:** *As regards producing a ministerial briefing with key points in relation to primary care extract, this was confirmed as completed and the action closed.* **EXISTING ACTION (43) UPDATED:** *As regards a paper outlining the proposed charging model (i.e. informed impact assessment, responsibilities, options, recommendations) for consideration by the programme board, the intention is still to bring this to a subsequent board.* The Open Actions Log accompanies these minutes. Any further updates or queries to be directed to davidfarrell@nhs.net
12	Any Other Business CO and PK gave the programme board an overview of the proposed European regulation for data confidentiality; PK explaining that the commission had drafted text for a general data protection legislation that would potentially repeal the data protection act in UK (it would be regulation) and spoke around the background and context of this area.
	Next Board meeting

	Monday 31st March 2014: 1.00 – 3.30 (Leeds and London VC)