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

Monday 25th November 2013

14.00 - 17.00

VC: Quarry House, Leeds (2E05); Skipton House, London (119D)

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

Dr Jonathan Kay Director of Clinical Informatics, NHS England

Eve Roodhouse Programme Head, Health & Social Care Information Centre (HSCIC)

David Farrell Programme Manager, HSCIC (and scribe)
Alan Barcroft Clinical Practice Research Datalink (CPRD)

Neil Stutchbury Monitor

lain Wallen Director of Information and Analytics, NHS Trust Development Authority

Peter Hall DH External Relations Directorate
Alistair McDonald NHS Business Services Authority

Chris Carrigan Public Health England

Martin Campbell NHS England, SRO for the National Tariff System (NTS) programme

Apologies:

Ming Tang Director, Data and Information Management Systems, NHS England

Max Jones Director of Information and Data Services, HSCIC

Dr Mark Davies Executive Medical Director, HSCIC

Siobhan Roberts Programme Communications for care.data

Oladunni Amode Care Quality Commission Tom Ward Care Quality Commission

Alexia Tonnel NICE

Peter Knight Deputy Director, Head of Research Information and Intelligence, Research

& Development Directorate, DH

Dr Martin Bardsley Head of Research, Nuffield Trust

Dr Jeremy Veillard Vice-President, Research and Analysis, Canadian Institute for Health

Information, University of Toronto

Dr Pete Green NHS Medway (CCG representative)
John Parkinson CPRD (Alan Barcroft deputised)
Jeremy Thorp Programme Delivery Director, HSCIC

Prof John Newton Chief Knowledge Officer Designate, Public Health England (Chris Carrigan

deputised)

Martin Hall Health Education England

Mike Foster Deputy Chief Executive, University College Hospital London

Karen Turner DH, Maternity and Children's programme (MCDS)

A Meeting governance and overview

1 Introduction, apologies and welcome to new members

Christine Outram (CO) welcomed everyone to the meeting, including those attending for the first time, and briefly outlined the role of the board.

2 Agenda overview and requests for AOB

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

She also reiterated that a lot of work is going on in the background in relation to planning (Brief, Prospectus, roadmap, Risk Assessment in line with assurance requirements) and these, along with the business case development – via the Strategic Outline Case (SOC) initially – will be brought to the board over the coming weeks and months as they are finalised.

3 Acceptance of minutes from previous meeting

The minutes from the board held on 1st October were accepted.

4 ISCG update

CO provided a verbal update of key messages from the recent ISCG, and invited others who had attended to add to this.

The impact of investment on data and technology and the impact on NHS costs and quality were highlighted as well as the need to work with all ALBs re defining a prioritised portfolio.

B Delivery

5-8 Delivery report

(covering items 5-8 on the agenda)

Eve Roodhouse (ER) presented the board report, highlighting a number of specific areas:

Strategic Outline Case (SOC): ER explained that this has now been developed, reviewed by NHS England programme team colleagues and is now in the assurance approvals process, currently with HSCIC Subject Matter Experts (SMEs) for their review and comment. The process beyond this is that it will be updated and distributed to programme board members for review (now anticipated early-mid Jan) and to wider SMEs (e.g. DH Finance) for endorsement and will go to the HSCIC Corporate Assurance Panel (CAP) and then on to the ISCG for their approval, before going forward for Cabinet Office and HM Treasury approval (all business cases with a cost over £50mn require HM Treasury approval and this business case is anticipated to be over that threshold).

Addendum Note (1):

A query was received (from Peter Knight) following the initial version of the minutes relating to the above (SOC) section 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.

EXISING ACTION (34) CLOSED – A full update as to progress of the business case is now a standing item as part of the delivery report going forward so this action has been closed.

NEW ACTION (39) - Distribute the Strategic Outline Case (SOC) for programme board review (now anticipated early-mid Jan).

<u>Programme Brief:</u> ER explained that this has been developed and is currently being reviewed by the programme teams in HSCIC and NHS England with a view to getting a solid, SRO

approved version to the HSCIC Portfolio Board for approval at their meeting on 18th December (update: a SRO-approved version has indeed been submitted to for this Portfolio Board). Approval by this HSCIC Portfolio Board will ensure formal presence on the work portfolio for the programme and will therefore align it formally with other programmes as regards programme controls (e.g. reporting, risk management, resource allocation).

The Programme Brief will be distributed to programme board members for review in advance of Christmas (update: this will be distributed w/c 16/12) with the anticipation that it should be updated and put forward for programme board approval at the end of January.

Note, the Brief will be followed by production of a Programme Definition Document (PDD) which will provide more detail as regards the individual delivery elements in the programme.

NEW ACTION (40) - Distribute the Programme Brief for programme board review (anticipated w/c 16/12) and seek approval from the programme board (anticipated at board on 28/1).

Risk Potential Assessment (RPA): ER explained that the RPA is a standard assessment that forms a key part and indeed kicks off the assurance process for the programme. It has been produced and is currently in the process of review, with a final version going, via the HSCIC Portfolio Office, to the Major Projects Authority (MPA) (update: the final, SRO approved version was submitted to the HSCIC Portfolio Office on 17/12). It is anticipated that the first assurance step (with the MPA) will be a Programme Validation Review (PVR) in early 2014.

<u>Primary – Secondary Care</u>: ER explained the phased rollout with extractions to take place from March to May. This phased approach over the 3 months extracts from 1% of GPs, then 10%, then 100% to enable quality checking and full testing of the process). Regular meetings with suppliers have also taken place in line with realising the plan.

A public announcement has taken place as regards the national leaflet drop due to take place from 6th January and this leaflet drop will be regional over 4 weeks with a patient line being readied in support of this. Accompanying digital media will be updated in support of this. Chris Carrigan asked how much clinical bodies are aware/have been engaged. ER responded that, in particular, the British Medical Association and the Royal College of GPs are aware and have been involved at length as regards the extract and the patient leaflet drop. Further discussion took place as to key bodies/areas to align/cover. It was agreed that there is a need to ensure the link up of NHS England, HSCIC, DH and Public Health England communications areas and Geraint Lewis took this as an action (for Rachel Merrett in his team); and it was agreed that a ministerial briefing with key points would be produced. In response to a more specific question as regards timing and what data will be extracted, ER explained that data will be extracted from the point of the first extract (i.e. by May the extract will cover Feb to May); that gaps as regards additional items (e.g. musculoskeletal) will not be plugged immediately as these will need to go back to the GPES Independent Advisory Group (IAG) for approval for inclusion; and that objections will be covered in a paper for the GPES IAG in January.

NEW ACTION (41) - Ensure the link up of NHS England, HSCIC, DH and Public Health England communications areas.

NEW ACTION (42) – Produce a ministerial briefing with key points in relation to primary care extract.

Maternity and Children's Data Set (MCDS): Good progress has been made since the last programme board, specifically around the Maternity data set, which was subject to a review. The outcome of this review was that all 3 data sets should proceed as against the original MCDS business case and a plan for delivery against all 3 should be in place for the next board. In response to a question as regards the size of the data set, ER explained that it has gone from over 1000 data items originally to around 170 now (been reviewed in line with need).

EXISING ACTION (38) UPDATED – Plan for delivery against MCDS data sets should be in place for the board on 28/1.

Index solution: Market engagement sessions have taken place as regards the Index solution

and enterprise wide de-identification tool. For clarity, this is not pseudonymisation at source; it is pseudonymisation as it leaves HSCIC.

<u>GP pathology</u>: ER explained how this fits with care.data (new data set flowing into HSCIC). The proposed approach with regards directions is that PHE colleagues will draft wording and NHS England will put together the directions based upon that wording.

Key Risks & Issues:

<u>Charging model:</u> The HSCIC data linkage commercial model, and feedback in relation to new charging model, was highlighted as a key risk. ER advised that Alan Perkins was about to formally respond to Chris Outram (as SRO) as regards the charging model and the implications on HSCIC.

Further discussion took place with Eve describing the charging model (i.e. reducing the charge to £1 and summary of implications).

Redacted – Section 41 FOI Act 2000

The intention is that, following consideration by the programme board (the board is a sub-group of the ISCG), recommendations should go forward to the main ISCG.

Geraint Lewis (GL) explained the thinking behind reduced charges in relation to involving small charities etc.

In response to a question as regards the shortfall from this charging model, ER explained that this was likely to be hundreds of thousands of pounds, rather than millions of pounds; and she also explained that HSCIC can't differentiate between who is charged what (i.e. charging commercial companies more than charities).

NEW ACTION (43) – In relation to the proposed charging model produce a paper (i.e. informed impact assessment, responsibilities, options, recommendations) for consideration by the programme board in advance of recommendations going forward to the main ISCG.

C Strategy

9 <u>Care.data prospectus</u>

Geraint Lewis (GL) explained the background to the prospectus (he had outlined at the previous board), in that its aim is to provide a vision for the programme. GL also explained the different covering letters that would accompany the prospectus, for different audiences, drawing out different points.

The draft prospectus is now ready for distribution for programme board members for their review and comment, with a view to publishing in January. Distribution to follow this meeting.

EXISING ACTION (12) UPDATED – Prospectus distributed (by David F on 26/11) for programme board members review and comment.

10 Related strategy items

PHE knowledge strategy consultation:

Chris Carrigan talked through the context of Public Health England (PHE) and data and what is needed. Analytics in PHE need to have access to data; PHE and partnerships can only deliver with partnerships with others (e.g. NHSE, CQC, care.data and common requirements) and that there is a big crossover with the objectives of care.data.

The consultation itself has had lots of responses and has just been extended, with responses due to be reported to the ISCG.

11 Hospital Dataset consultation update

GL presented an overview (update) from the recent Hospital Dataset consultation – slides to accompany these minutes and a full paper to be prepared for the board.

EXISING ACTION (10) UPDATED - Presentation slides (in relation to consultation) to be

distributed to programme board members and a full paper to be prepared for the board. **Other Business** D 12 Other papers for information and acceptance There were no other papers for information and acceptance at this board. 13 Review of remaining open actions (i.e. a review of those actions from the Open Actions Log due for review and not addressed during by previous agenda items during the meeting) EXISING ACTION (29) UPDATED - It was agreed that David F will chase progress of this action and update (relates to a proposal put forward by John Parkinson at the May 13 programme board: 'Implantable Devices - adding a field to HES'). **EXISING ACTION (37) UPDATED –** In relation to ensuring appropriate patient representation for care.data, this is still with the Patient and Public Voice (PPV) area within NHS England (would like to align with how other programmes are involving patient representatives) and this is being followed up. The Open Actions Log accompanies these minutes. Any further updates or gueries to be directed to davidfarrell@nhs.net 14 Any Other Business David F reported that, outside of this board (as he was unable to attend this board), Tom Ward (CQC) has indicated that he would be happy to present to the programme board in relation to the Strategy for Data on Quality and how it relates to care.data. **NEW ACTION (44)** – CQC to present to a later programme board in relation to the Strategy for Data on Quality and how it relates to care.data. **Next Board meeting** Tuesday 28th January 2014: 2.00 - 4.30

(Leeds and London VC - diary invite to follow)