care.data
Programme Board

Wednesday 16th July 2014

15:00 – 17:00

VC: Skipton House, London and Quarry House, Leeds

MINUTES

Attendees:

Tim Kelsey	Care.data Senior Responsible Owner (SRO)
Eve Roodhouse	Care.data Programme Director
Dr Geraint Lewis	Chief Data Officer, NHS England
Belinda Quinn	Clinical Practice Research Datalink (CPRD) (on behalf of Dr Ian Hudson)
Prof John Newton	Chief Knowledge Officer, Public Health England
Peter Knight	Deputy Director R&D, Head of Research Information & Intelligence, DH
Graham Binns	Monitor (on behalf of Neil Stutchbury)
Simon Denegri	National Institute for Health Research
Tom Ward	Care Quality Commission
Ola Amode	Care Quality Commission (request of Tom Ward)
Eva Simmonds	Care.data Programme Manager (Business Case Lead) (request of Eve)

Apologies:

Dr Ian Hudson	CEO, Medicines and Healthcare products Regulatory Agency (MHRA)
Will Cavendish	Director General - Innovation, Growth and Technology, DH
Neil Stutchbury	Monitor
Andy Williams	CEO, Health & Social Care Information Centre
Ciaran Devane	Chair of the care.data Advisory Group

Secretariat:

David Farrell	Care.data Programme Team
Donna Braisby	Care.data Programme Manager (Controls and Governance)

1 **Welcome, introductions and apologies**

Tim Kelsey (TK) welcomed members and noted apologies received.

He explained that this was the second meeting of the reconvened programme board and that membership is still being finalised in a couple of areas:

- Sam Everington (Tower Hamlets CCG) had been invited to attend and has subsequently suggested a replacement (this is being followed up)
- Ciaran Devane, as Chair of the Advisory Group, has been invited to attend. *(subsequent note: Ciaran put this to the Advisory Group on 18th July and it was agreed he should attend subsequent board meetings to provide link/updates but not as a member)*
- Appropriate clinical representation is being progressed by TK

Additionally, members were encouraged to nominate a deputy to attend meetings should they be unable to.

2 **Agenda overview and requests for AOB**

TK then provided an overview of the agenda. There were no requests for AOB at this point.

3 **Acceptance of minutes from last meeting and review of actions**

(Paper 01: 'Programme Board Minutes 20140625' – *for acceptance*)

Outcome: The minutes from the board meeting held on 25th June were accepted as submitted.

4 **Programme background and key messages**

TK talked through a number of key items:

- He reiterated that the decision to extend the engagement period, and the subsequent impact upon delivery date from original, was part-attributable to the way in which the team worked previously and that, with the recent Project Validation Review (PVR) as the driver, the newly revised governance has had a positive impact.
- Resource issues still exist across the programme and the programme team is still not up to full numbers
- The programme is moving to the recruitment of a number of pathfinder GP practices in relation to the primary care extract activity. The intention was to formally launch recruitment in the week of the board meeting but there is a slight delay whilst the approach is being fully assured (although this will not delay delivery of the overall programme).
- TK attended the Health Select Committee on 1st July and felt that this was positive, that there was no pushback on the programme itself. One of the key points made was that we need to communicate in new ways.

5 **Board highlight report and plan**

(Paper 02: 'Programme Board Highlight Report' – *for information*)

Eve Roodhouse (ER) talked through the highlight report, drawing out a number of key points:
General:

- The overall RAG reporting status for the programme has changed to Amber/Red in response to board feedback at the last meeting, particularly as regards there being no business case in place, or indeed funding sources to support some areas. This Amber/Red rating also balances better against the individual areas within the report.

Stakeholder, Communications and Engagement:

- The original intention was to get Expressions of Interest letters out to CCGs in the week of this board but this has been delayed as the approach (and letter itself) is being fully assured

(Subsequent note of update: the approach has since been re-evaluated and a number of CCGs will now be approached to become involved, rather than a letter going out to each – ER has since written to board, and Advisory Group, members to explain).

- As the listening period progresses with a number of events being held, there is a need to feedback, including to the board, on what we have heard. A summary document will be prepared to do just that.
- Research work is progressing with Ipsos MORI leading a number of events (including first one on weekend previous to this board meeting) and – by way of an informal update from the first session – people found the event interesting and it is very clear that this research work is informative in ensuring clear what the public want.
- Creative agency has been selected and we are finalising the procurement process.
- Recent meeting with the BMA reiterated their view that there is a need to further investigate/test the sending of individual letters. The potential burden on GPs regarding fair processing was also expressed again (feeling in relation to pressures on GP environment) and it is likely that this will be picked up again in discussions with NHS England.

It was noted by the board from this update that the subject of individual letters may potentially have big implications on costs.

Peter Knight (PK) reiterated the importance of being very clear on the language being used in public events versus legal terms (e.g. 'opt out' versus 'object'). Geraint Lewis (GL) said that – from the events he had attended - feedback from some (public) attendees was that the term 'object' was perceived as a feeling but 'opt out' is perceived as an action (so yes, clarity of language is very important). ER explained that the Ipsos MORI output needed to be impacted on the objection text and forwarded for SofS approval. The Planning Principles (one of the documents previously seen by the board and included as a supporting paper here) had been updated to reflect this.

New action taken: Feedback from the research events will be documented and circulated (and/or presented) to the board.

Policy and Commissioning:

- The roadmap for extending the primary care data set is to be taken to the Advisory Group meeting on 18th July for them to see/advise on and the intention is to come back to the board following this Advisory Group review.

John Newton (JN) reiterated the need to get the scope correct at this point, and TK explained that the intention is definitely to expand but only where this is supported with a clear plan to do so.

JN also pointed out that the availability of historical data within the primary care data set (currently not included in agreed extract) is likely to be a key issue for introducing further/future iterations (the roadmap). TK thought that there will be points where we have to go back to the public and defining these correctly is important to both the public and to GPs.

PK raised a question around whether research use was not explicitly agreed previously and it was explained that research is not covered however public health is. However the position needs to be clarified/confirmed at the Sept IAG (in advance of any pathfinder extract commencement)

New action taken: Provide, for board review and approval, the roadmap for extending the scope of the primary care data set (following Advisory Group feedback).

New action taken: Seek (IAG) assurance that agreed access covers PHE/CQC/Other ALBs – to explicitly re-confirm for the board.

Technical Delivery:

- The team is working with suppliers and moving the technical solution forward. It is HSCIC policy that all data should be landed in an IL4 (accredited secure) data centre and that a business justification for the platform (Strategic Capability Platform Phase 1) has been prepared for HSCIC approvals/sign-off. Although this business justification does not need to go wider for approvals, DH is providing scrutiny via a Gateway Review.

In response to a question as to why the policy was to land in an IL4 accredited date centre, and not IL6, ER explained that this is corporate policy and that there is existing infrastructure (and precedent) in the HSCIC associated with other programmes, such as e-Referral Service and Spine.

Controls and Governance:

- Eve explained that the new Programme Manager for Controls and Governance is now in place (Donna Braisby). The Programme Head for Data Delivery (David Corbett) and a Programme Head for Strategic Capability Platform (David Ibbotson) are also now in place. Eva Simmonds (Programme Manager), who attended this board meeting to talk through the business case approach, is now leading development of the business case.

A discussion took place regarding the board's role at decision making points, what reporting they require to support this. PK asked for further clarity on what assurance will be provided to the Programme Board to inform decision making (e.g. IIGOP) and it was agreed that the programme team would be provide details of what reports and other materials would be provided to inform the decision to extract data and then to assess the success of the pathfinder stage.

New action taken: Provide details of what reports and other materials would be provided to inform the decision to extract data and then to assess the success of the pathfinder stage.

Note of clarity: the following was confirmed with Alan Hassey, IIGOP, and submitted for the National Information Board to clarify their role:
"A revised plan for the delivery of primary-secondary care linked data for a number of 'pathfinder' GP practices is in place and the programme is progressing against this. The key elements for this are the delivery of a number of pre-requisites (including technical readiness and appropriate stakeholder and public engagement) to enable the programme board to decide whether the pathfinder stage can launch. The implementation of the primary care extract for pathfinder GP practices will launch only when the board is happy for it to and they will make their decision based (amongst other things) on advice received from the Independent Information Governance Oversight Panel (IIGOP) and the care.data Advisory Group. When launched, the success of the pathfinder stage will be evaluated before any decisions on future rollout activity are taken by the programme board (again informed by independent advice)".

Some direct feedback was provided in relation to the highlight reporting including the need to add movement/direction for the risks.

New action taken: Add movement/direction of risks when presenting via the highlight report.

6 **Project Validation Review (PVR) action plan**
(Paper 03: 'PVR Action Plan' – *for approval*)

Redacted – Section 36 FOI Act 2000

[redacted]

[redacted]

[redacted]

Redacted – Section 36 FOI Act 2000

Outcome: The PVR action plan was approved as an appropriate mechanism to track against the PVR recommendations and should be made available for the board at future meetings.

New action taken: The PVR action plan to be a standing board paper; and the actions detailed in the PVR action plan to be incorporated into the overall programme timetable plan.

New action taken: Provide, for board review and approval, a detailed plan for the Pathfinder stage.

7 **Business case approach**

(Paper 04: 'Business Case Approach' – *for information; with proposed overarching approach for approval*)

Eva Simmonds (ES) presented the proposed approach for development of the care.data business case:

- The central point is the development of a Programme Business Case (PBC), with individual components being represented by business cases/business justifications falling from this – this follows new Cabinet Office guidelines/approach to business case development.
- The Programme board and other approval bodies (National Information Board/Department of Health/Treasury) would be signing off an envelope of funding and detailed costs/funding requests would follow in the next level business cases/business justifications.
- Being clear who is responsible for delivery of the Strategic Capability Platform is a key scope area for the programme and this approach will ensure this is clear (i.e. the overarching care.data PBC will provide overall context and the next level 'SCP business case' would have associated assurance/governance with it).

The board agreed that, whilst it was important to keep SCP in scope, there needed to be clear wording in the PBC to ensure clarity around accountability of delivery for this board in relation to, particularly, the HSCIC Board which has a major interest in delivery of this infrastructure.

PK said that whoever is providing assurance/governance for the component areas must therefore provide assurance – for this programme board - that they are going through due process at the next level.

JN asked about the total cost (how do you know it at the PBC level?). The approach means that total cost is at a high level (an educated guess with assumptions and with optimism bias built in, very much like an Outline Business Case (OBC)).

Discussion followed around other scope areas. All agreed that the scope/vision needs to be driven by the outcome first this needs to be driven by the outcome first (e.g. safety of patients based on data), then all will fall from this. Also, comms and engagement, Information Governance, programme governance, management of service, and standards, all need to be

included.

The board agreed to commit to a further development session to provide detailed input into the scope/vision for the business case development process.
The board also requested a proposed timeline for the development and approval of the PBC.

New action taken: Arrange a further development session to provide detailed input into the scope/vision for the business case development process (all board members to be invited).

New action taken: Provide a proposed timeline for the development and approval of the PBC for board information.

Outcome: The board approved the proposed business case development approach (i.e. Programme Business Case (PBC), with individual components being represented by business cases/business justifications falling from this).

8 **AOB**

The following documents were submitted as supporting papers for baselined approval:

- Paper 05: 'Programme Board ToR'
- Paper 06: 'care data Pathfinder Proposal'
- Paper 07: 'care.data Planning Principles'

Outcome: The Programme Board ToR (Paper 05) was approved for baseline; the Pathfinder Proposal and Planning Principles documents (Papers 06 and 07) would be updated further following specific feedback and resubmitted.

New action taken: Update the Pathfinder Proposal and Planning Principles documents (including changing 'data lab' terminology and revised CCG engagement approach) and resubmit for the board.

Next Board Meeting
Tuesday 26th August 2014: 2.00 – 4.00
(VC: Skipton House (6B6) and Quarry House (4W25)

Open Actions

From 25/06/14 meeting:

1. Ask someone from the Clinical Advisory Group to become a member of the board *(allocated to Tim Kelsey).*

2. It has been the intention of the current SRO that the Director of Intelligence in NHS England (role being advertised) would take over as the SRO for care.data when appointed. It was queried whether the successful candidate would be a full time SRO and Will Cavendish and Tim Kelsey agreed to have a further separate discussion regarding this *(allocated to Will Cavendish and Tim Kelsey).*

3. Board to consider an appropriate approach to communicating with previous member organisations/other stakeholder members (*allocated to Eve Roodhouse*).

From 16/07/14 meeting:

4. Feedback from the research events to be documented and circulated (and/or presented)

	to the board *(allocated to Eve Roodhouse).* 5. Provide, for board review and approval, the roadmap for extending the scope of the primary care data set (following Advisory Group feedback) *(allocated to Eve Roodhouse)*. 6. Seek (IAG) assurance that agreed access covers PHE/CQC/Other ALBs – to explicitly re-confirm for the board *(allocated to Geraint Lewis)*. 7. Provide clarity on what assurance is taking place around the decision making areas of the programme (e.g. IIGOP) for the board; and provide the pre-requisites/dependencies for pathfinder extract commencement for the board (these will be followed subsequently by the success criteria that would be examined post-extract) *(allocated to Eve Roodhouse)*. 8. Add movement/direction of risks when presenting via the highlight report *(allocated to Secretariat)*. 9. The PVR action plan to be a standing board paper; and the actions detailed in the PVR action plan to be incorporated into the overall programme timetable plan *(allocated to Eve Roodhouse and Secretariat)*. 10. Arrange a further development session to provide detailed input into the scope/vision for the business case development process (all board members to be invited) *(allocated to Eve Roodhouse (Eva Simmonds organising)).* 11. Provide a proposed timeline for the development and approval of the PBC for board information *(allocated to Eve Roodhouse)*. 12. Update the Pathfinder Proposal and Planning Principles documents (including changing 'data lab' terminology and revised CCG engagement approach) and resubmit for the board *(allocated to Eve Roodhouse)*.