care.data
Programme Board

Tuesday 26 August 2014

14:00 – 16:00
VC: 6B6 Skipton House, London and 4W25 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
Prof John Newton	Chief Knowledge Officer, Public Health England
Neil Stutchbury	Monitor
Graham Binns	Monitor
Simon Denegri	National Institute for Health Research
Dan Wellings	NHS England (Ipsos MORI Feedback on request of Eve)
Andy Williams	CEO, Health & Social Care Information Centre

Apologies:

Dr Ian Hudson	CEO, Medicines and Healthcare products Regulatory Agency (MHRA)
Will Cavendish	Director General - Innovation, Growth and Technology, DH
Ciaran Devane	Chair of the care.data Advisory Group
Peter Knight	Deputy Director R&D, Head of Research Information & Intelligence, DH
Tom Ward	Care Quality Commission
Bethan George	Deputy Director Integrated Care WELC Integrated Care Program Tower Hamlets CCG
Sir Bruce Keogh	National Medical Director

Secretariat:

Donna Braisby	care.data Programme Manager (Controls and Governance)
	care.data Programme Support Office

Redacted – Section 40 FOI Act 2000

1	**Welcome, introductions and apologies**
	Tim Kelsey (TK) welcomed members and noted apologies received.
	• It was noted that clinical representatives were not in attendance. Sir Bruce Keogh's Office declined this invitation and Martin McShane is named as a deputy (In Sir Bruce's absence). However neither could attend this Programme Board. TK will follow this up.
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' – *for acceptance*)
	Outcome: The minutes from the board meeting held on 16 July were accepted as submitted.
4	**Board highlight report and plan** (Paper 02: 'Programme Board Highlight Report' – *for information*
	Stakeholder, Communications and Engagement: • Ipsos MORI feedback sessions have been delivered to both the programme team and also the Advisory Group. The presentation would be delivered to the Programme Board later in the meeting. • Creative agency DLKW Lowe has been appointed. They have received their brief and have been working closely with Ipsos MORI. They have initially developed three concepts and are committed to working with the pathfinders.
	Policy and Commissioning: • The process for SofS sign off for the objection wording was discussed. • Eve Roodhouse (ER) advised that IIGOP have advised informally that, having seen a draft of our briefing, they plan to write to Will Cavendish to highlight where policy needs to be clearer.
	TK advised the SofS sign off was required in high level terms and key stakeholders need to be content prior to this.
	Andy Williams (AW) stated that he understood the issues to be around the wider position on handling objection/consent in the system rather than specific to Care.data.
	Data Delivery: • CCGs who had expressed an initial interest in becoming pathfinders were being informally engaged in order to gather information. • CCG selection panel is taking place on 27 August with ER as chair.
	Technical Delivery: • Decision taken Friday 22 August to not proceed at this stage with new technical platform. AW advised this decision was based upon: the timescales for procurement and possible implications of fast tracking; and, the finance and possible implications of components of the proposed platform not being re-used, particularly in light of the fact that with lower initial volumes data can be landed on an existing platform. This will allow more focus on the strategic capability platform. • ER highlighted to the Board that the data centre which forms part of the existing technical

5	platform is IL3 and not IL4, which was the standard the programme team had been working to in building a new technical platform.AW did not consider this to be an issue as all of HSCIC will eventually move to IL4 and data collected as part of care.data will be part of this process. TK also assured the board that Max Jones is satisfied that IL3 is sufficiently secure.

Outcome: The board therefore agreed that there is no potential issue or risk relating to the care.data pathfinder data being landed on IL3 platform.

Jon Newton (JN) asked once this data is received and linked with HES, how will this then be analysed. ER advised a significant amount of work has already been completed and during the pathfinder stage the analysis will be completed in Leeds as this is the only physical location. ER stated there will be constraints on the number of analysts due to the secure data facility layout. JN stated the sooner the analysts were able to complete their assignment the more effective lessons learned would be. TK suggested a joint analyst team in order to maximise the potential. Neil Stutchbury (NS) asked whether the data will be accessible remotely post pathfinders. TK responded that his commitment at the Health Select Committee still stood. The NIB strategy is moving towards remote access and the same should apply for care.data. However work in this area needs to be completed going forward. Graham Binns (GB) asked how care.data would progress index and pseudonymisation within the new approach. ER stated the impact analysis has yet to be completed, more would be known at that point.

New action taken: ER to confirm what analysts would be working on the data and what outputs can be expected. Presentation to be presented to the board on 23 September 2014.

Controls and Governance:
- Ciaran Devane is leaving his position as CEO for Macmillan in October 2014 and some clarity is required for his capacity to continue to chair the Advisory Group and as a programme board member (advice only)
- TK stressed the urgency for a robust review of risks and issues.
- TK advised that a Gateway 0 review by the Major Projects Authority (MPA) needs to be booked in ASAP

New action taken: ER to discuss Ciaran Devane's capacity to continue as chair of the Advisory Group on 8 September 2014.

New action taken: Risk and issues process and log to be revisited in order to be baselined by Programme Board.

New action taken: Gateway 0 review to be scheduled.

Business Case:
- TK asked for a timetable for the business case to be developed and presented to the board on 23 September 2014.

New action taken: Timetable for Business Case to be developed for scrutiny and review by Programme Board

5	**Pathfinder Plan**

(Presentation Paper 03: 'Detailed Pathfinder Plan' – *for approval)*

Key Milestones:

- It has been agreed that the Pathfinder CCGs will be confirmed in September 2014; data extraction for visible support in Secure Data Facility is scheduled to take place in January 2015.
- AW stated the need to have an extra milestone included to reflect when analysis will be completed and output will be available.
- A further milestone was suggested to assess the success of the pathfinder stage

Key Risks:
- NS raised the fact that no funding neither source of funding had been agreed for pathfinders, which could result in a delay on the delivery timescale. TK confirmed that NHS England had funding to cover costs in this financial year. ER flagged that there remained some uncertainty regarding funding for HSCIC resources. AW advised TK that it was covered in the letter he sent regarding finances on 15 August 2014.
- NS also raised the timing of the election and whether it would impact delivery of the programme. TK provided assurance that the programme was well supported and no problems were envisaged at this stage.

New action taken: TK to consider available funding for care.data to based on the letter AW issued on 15 August 2014.

Controls and reporting:
- The board approved this section without comments

Outcome: Board accepted the timeframes with the need for extra milestones to be added and represented

6	**Roadmap – Primary care dataset**

(Paper 04: 'Roadmap to extend the primary care data set' – *for approval*)

- ER set the context for the paper, she advised the board that an earlier version of the paper had been shared with the Advisory Group and their feedback had been taken into consideration. She also advised the group that work was in hand to submit a request to the GPES IAG to request that access to the existing dataset be expanded.
- JN stated that we are taking the right approach, using analysis of the data extracted during the pathfinder stage to understand any limitations of the existing dataset and to make the case for expansion will be important. The board agreed this places even more emphasis on the work to be done by analysts during the pathfinder stage and requested that the scope of that work be outlined to the Board at their next meeting.

Outcome: Board approved the approach proposed. Specifically:
1. **We will only seek to expand access to the existing dataset (i.e. for non-commissioning purposes) in the pathfinder stage NOT the scope of the dataset itself (i.e. the codes collected from GP practices) and not to move to accept section 251 approvals in relation to disclosures from the HSCIC.**
2. **We will conduct a consultation on how to expand the dataset only once the pathfinder stage has concluded.**

7	**Documentation and evidence to inform decision for extraction**

(Paper 05: 'Documentation and evidence to inform decision for extraction' – *for approval*)
- Approvals and governance process should be clarified through IPEG to avoid any issues.
- The views of the Care.data Advisory Group will be represented at decision points through the Chair's attendance at the Programme Board to act as their 'voice'.
- The document needs to be expanded in order to set out what evidence should be

	provided to the Programme Board to inform their decision about whether the pathfinder stage itself has been a success. **New action taken: Documentation and Evidence to inform decision for extraction paper to be expanded to incorporate the success.**
8	**Selection process for CCG's** (Paper 06: 'CCG Approval and Selection Process' – *for approval)* • The board had no comments surrounding this paper. **Outcome: Board approved the CCG Approval and Selection Process paper**
9	**Ipsos MORI Research Feedback** (Presentation Paper 07: Ipsos MORI Feedback' – *for information)* • Dan Wellings (DW) reiterated the importance of using of a clear and transparent language and communication during public events, particularly in 3 main key areas: Security (identification of the bodies having access to the data is necessary), Opt out (difference between "Objection" and "Opt out") and Access (the possibility for an access at national level was discussed). • It was mentioned that although GP's and practitioners saw clear benefits and values of the programme they do not have enough knowledge about it and too many points remain unclear, they are concerned that this could affect the relationships they have with their patients. • JN confirmed that there was a lack of clarity regarding what care.data was about. • Simon Denegri (SD) thought the investment had been very worthwhile and considered it important for this to continue going forward. He also stated that the public opinion and reception could be an issue. • DW stated that the costs attached to a national campaign about the programme have not been evaluated and asked what would be the process of evaluation of the pathfinders.
10	**Project Validation Review (PVR) action plan** (Paper 08: 'PVR Action Plan' – *amended version*) • ER asked for feedback from the programme board via e-mail of the amended PVR action plan.
11	**AOB** *The following documents were submitted as supporting papers:* Paper 09: 'care.data Planning Principles' *amended version* • Provided to the board for information based on updates agreed to be made in Programme Board 16 July 2014 Paper 10: 'Engagement Report (covering period from February 2014)' – *for review* • SD stated that the focus should be on investigating on the key points of the report. SD pointed out some issues with the report. Firstly it doesn't show the link between the engagement report (formerly 'you said we did' – YSWD document) and the Ipsos MORI feedback. Secondly the report has consequent hazard warnings, which are not positive and finally the response is not robust enough. **New action taken: ER to consider how the engagement report will be presented with SD.**

	Paper 11: 'care.data draft Narrative' – *for information*
	• This document was provided for the board as information only as further work is required in this area linked with the creative agency. The board accepted.
12	**Next Board Meeting** Tuesday 23 September 2014: 11:30 – 13.30 VC: Skipton House (6B6) and Quarry House (4W25)
13	**Open Actions** From 25 June 2014 meeting:

1. Ask someone from the Clinical Advisory Group to become a member of the board *(allocated to Tim Kelsey)*.
   - *Sir Bruce Keogh (or deputy – Martin McShane) unable to attend Programme Board on 26 August or Business Case vision and scope session on 17 September. ER to draft note for TK to send.*

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).*
   The intention is still to have a permanent SRO, however recruitment currently on hold to allow 'at risk' senior managers the opportunity to apply prior to external recruitment (if required)

3. *Board to consider an appropriate approach to communicating with previous member organisations/other stakeholder members (allocated to Eve Roodhouse).*
   Number of organisations no longer represented who require to be updated on care.data. ER to agree regular updates.

From 16 July 2014 meeting:

4. Feedback from the research events to be documented and circulated (and/or presented) to the board *(allocated to Eve Roodhouse).*
   Presented to the board on 26 August 2014.

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).*
   Provided and discussed with the board on 26 August 2014.

6. Seek (IAG) assurance that agreed access covers PHE/CQC/Other ALBs – to explicitly re-confirm for the board *(allocated to Geraint Lewis).*
   GPES has an advisory group to discuss whether requests are reasonable OR APPROPRIATE. This clarifies all related purposes. IAG have stated there are 5 criteria which they need to assured on, and the paper needs to be amended to reflect this. ER advised the paper is going to the September IAG board but this would allow ample time to make the amendments that are required.

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).*
   Provided and discussed with the board. Amendments to be made and re-presented on 23 September 2014.

8. Add movement/direction of risks when presenting via the highlight report *(allocated to Secretariat)*.
   Risk register to be presented to the board on 23 September 2014 to be baselined.

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)*.
   Revised PVR report provided to the Programme Board, comments to be in writing to ER. PVR is now a standing agenda item.

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))*.
    Session is now scheduled for 17 September 2014 from 10:00 – 12:00. All board members were encouraged to attend.

11. Provide a proposed timeline for the development and approval of the PBC for board information *(allocated to Eve Roodhouse)*.
    Milestones provided in pathfinder plan, however the board would like to see a specific timeline for the business case.

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).
    Data Lab terminology changed in the Planning Principals document which was re-submitted to the board for approval on 26 August 2014. This approval was agreed.

From 26 August 2014 meeting:

13. Confirm what analysts will be working on the data after extraction and what outputs can be expected *(allocated to Eve Roodhouse)*.

14. Clarify Ciaran Devane's capacity to continue as chair of the Advisory Group on 8 September 2014 *(allocated to Eve Roodhouse)*.

15. Risk and issues process and log to be revisited and presented to the Programme Board for baselining on 23 September 2014 *(allocated to Eve Roodhouse)*.

16. Gateway 0 review to be scheduled *(allocated to Eve Roodhouse)*.

17. Timetable for Business Case to be developed for scrutiny and review by Programme Board *(allocated to Eve Roodhouse)*.

18. Available funding for care.data to be considered based on AW letter dated 15 August 2014 *(allocated to Tim Kelsey)*.

19. Documentation and Evidence to inform decision for extraction paper to be expanded to incorporate success then represent to the Programme Board *(allocated to Eve Roodhouse)*.

20. Discuss the way in which the engagement report will be presented to the Advisory Group (allocated to Eve Roodhouse and Simon Denegri)