

**care.data
Programme Board**

Wednesday 15 October 2014

15:00 – 17:00

VC: 6B6 Skipton House, London and 4W25 Quarry House, Leeds

MINUTES


Attendees:

Phil Bastable	Head of Marketing, NHS England
Graham Binns	Monitor
Alan Barcroft	Department of health, on behalf of Peter Knight
Mark Davies	Director of Informatics and Digital Strategy, Department of Health
Jon Ford	CPRD Head of Operations, MHRA, on behalf of Ian Hudson
Bethan George	Deputy Director Integrated Care WELC Integrated Care Programme Tower Hamlets CCG
Tim Kelsey	Care.data Senior Responsible Owner (SRO)
Dr Geraint Lewis	Chief Data Officer, Patients & Information, NHS England
Martin McShane	Domain Director for Long Term Conditions, on Behalf of Sir Bruce Keogh
Eve Roodhouse	Care.data Programme Director
Tom Ward	Head of Intelligence and Information Management, CQC
Andy Williams	CEO, Health & Social Care Information Centre

Apologies:

Will Cavendish	Director General, Innovation, Growth and Technology, Department of Health
Simon Denegri	National Director for Public Participation and Engagement in Research, NIHR
Ciaran Devane	Chair of the care.data Advisory Group
Sir Bruce Keogh	National Medical Director, NHS England
Peter Knight	Deputy Director, information and Intelligence, Department of Health
Prof John Newton	Chief Knowledge Officer, Public Health England
Sarah Schofield	Chair NHS West Hampshire CCG
Neil Stutchbury	Knowledge Management Director , Monitor

Secretariat:

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

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1	<p><u>Welcome, introductions and apologies</u></p> <p>Tim Kelsey (TK) welcomed members and noted apologies received.</p>
2	<p><u>Agenda overview and requests for AOB</u></p> <p>TK then provided an overview of the agenda.</p>
3	<p><u>Acceptance of minutes from last meeting and review of actions</u> (Paper 01: 'Programme Board Minutes 20140923' – <i>for acceptance</i>)</p> <p>Outcome: The minutes from the board meeting held on 23 September were accepted as submitted.</p>
4	<p><u>Board highlight report and plan</u> (Paper 02: 'Programme Board Highlight Report 20141015– <i>for information</i>)</p> <p><u>Overall delivery confidence commentary</u></p> <ul style="list-style-type: none"> • TK confirmed that the names of CCGs for the pathfinder stage had been announced and are Leeds (North, West, South and East), Blackburn with Darwen, West Hampshire and Somerset. He noted that some media coverage had followed, including the Daily Mail, the Guardian and BBC Radio 4. • Eve Roodhouse (ER) informed the board a case conference had been held related to the programme business case for care.data with Department of Health (DH) on 9 October 2014. The outcome was to agree to treat the pathfinder stage as a discovery phase so that costs can be accounted for via an ICT spend approvals form. The Programme business case will continue to be developed alongside at pace. • Recruitment across the programme is underway and 12 new resources will join the team during October-December 2014 (quarter 3). • Major Projects Authority has been updated on the Project Validation Review (PVR) recommendations. Gateway 0 initial assessment meeting is scheduled for 27 October 2014, with the review expected to take place in January/February 2015. • ER stated that business planning for the next financial year is progressing with HSCIC and NHS England. • The Summary of Engagement and next steps document (formerly You Said We Did) has been submitted to the Board for review ahead of publication. <p><u>Stakeholder engagement and media</u></p> <ul style="list-style-type: none"> • A HSJ round table on care.data took place, including the participation of TK and other participants from RCGP/BMA, MedConfidential, Science Media Centre, National Voices and Patients4data. • The report from this roundtable is scheduled to be published on the 24 October. <p><u>Commissioning strategy and policy</u></p> <ul style="list-style-type: none"> • ER stated that the Objection wording/Opt-Out had now been approved by the SofS and reviewed by IIGOP. The next step will be to develop detailed FAQs. ER confirmed to the board that the wording was not specific to care.data but related to all flows of identifiable data leaving the GP practice for purposed other than direct care. • Martin McShane (MM) asked whether risk stratification or invoice validation were considered direct care. • Tom Ward (TW) asked if the patients would understand that when a patient opts-out this would stop all identifiable data leaving the practice not just to HSCIC. ER advised work was underway with pathfinders to ensure this was communicated effectively to patients. Mark Davies (MD) also stated that DH is working on a legal direction to be issued to the HSCIC to clarify the position on objections. • Geraint Lewis (GL) proposed that further clarification was needed, as to when the Opt out would or would not apply, particularly in relation to other ALBS. It was agreed that DH should issue guidance and write to all ALBS regarding the implementation of the objection. • Jon Ford (JF) advised that CPRD had been tracking objection codes and would share findings.

- ER stated that there was a requirement for clear guidance for GPs as to their legal obligations with regards fair processing and that the ICO guidance would be shared with pathfinders for feedback.
- ER advised that Ipsos MORI will carry out polling in pathfinder areas to inform what kind of communication methods (e-mail, letters, text messages) work best for patients. She added that delivering letters to every patient would incur a high cost for the taxpayer although concerns relating to e-mail coverage in GP practices have been raised. Consideration needs to be given to discuss what support GP practices require to improve this situation so that this channel of communication can be used more readily.

New action taken: Objection wording as approved by S of S for testing with pathfinders to be circulated to Programme Board members.

New action taken: CPRD to share findings related to objection codes.

New action taken: DH to issue guidance and write to all ALBS regarding the implementation of the objection.

5 **Risks and issues**

Additional risks and issues were identified and discussed during the session:

- GL raised the fact that adverse media coverage was one of the biggest risks for this programme and should be added to the register.
- It was discussed and agreed that Risk number 1 (Purdah/Election) was not a risk for the programme and should be removed. Risk number 7 (Lack of resources across programme) is reducing and did not feel like a top risk.

Outcome: The highlight report was discussed and reviewed by the Programme Board and the risk and issues section will be amended.

6 **Pathfinder plan**

(Presentation Paper 03: Pathfinder stage plan 20141015 – for approval)

- ER summarised the key milestones of the Pathfinder stage plan
- Jon Ford (JF) (CPRD) offered to support data validation activity to support the analysis stage.
- ER underlined that the key approval sought from the Board would be to commence fair processing and proceed to data extraction as this is not a pilot for patients involved. IIGOP and the Programme Board will monitor the fair processing period to ensure it proceeds to plan.
- It was stated that the HSCIC will have the role to ensure the quality of data set and linkage in relation to analysis.
- GL added that some countries have been doing such linkage for years and recommended to take example from them in relation specifically with to analysis.

Outcome: The Pathfinder Plan was approved by the Board.

7 **Assurance, Approval and Evaluation for Pathfinders**

(Paper 04: 'Assurance, Approval and Evaluation for Pathfinders' – for approval)

- ER stated that this paper was a key document, which sets out the proposed approval process for the decision to commence fair processing and subsequent extraction.
- A question was raised from the board, asking what security arrangements would be in place on the Data Management Environment (DME) and who would be able to access the Secure Data Facility (SDF) once it is available. Andy Williams (AW) explained that the HSCIC DME will be signed off by the SIRO and the Caldicott Guardian following extensive testing.
- GL noted that the papers would greatly benefit from explicitly showing who takes important decisions. Advice must be first sought from IIGOP and Dame Fiona Caldicott, then formal approval will be sought from HSCIC board, the Department of Health and the Programme Board for final approval.
- A check point is required by the Programme Board in between fair processing and extraction

New action taken: It was agreed that the Programme team would take GB through the test plan.

New action taken: Assurance, approval & evaluation for pathfinders paper requires updates prior to approval by board.

8 Creative Path

(Presentation Paper 05: 'Creative Approach Presentation 20141015' – *for information*)

- The approach will focus on demonstrating benefits at a population level rather than at the individual level, it should set out how sharing data will help to deliver those benefits, and how privacy will be protected, notably with the right to Opt-out.
- 3 creative paths or “routes” have been tested with the public by Ipsos MORI:
- - Route 3 was the preferred option in the focus groups held. Following feedback the design has been tweaked to reduce the pixels, making it easier to notice the symbols. However due to the need to co-produce with the pathfinders further work will be ongoing to ensure the agreed process is followed.
- ER added that on a digital version the symbols could be interactive.
- TW suggested that we should explain to people what are the “consequences” when people Opt-out.

Outcome: The Creative approach was well received. Communication materials will be further discussed during an Advisory sub group session that will take place on the 17 October.

9 Engagement Summary Presentation (Formally 'You Said, We Did')

(Presentation Paper 06: Engagement summary (formally YSWD) 20141015 – *for approval*)

- TK stated that the document needed further review before being approved. A sentence should be added at the beginning of the document, to engage with the readers for feedback and to ensure they are aware this is a live document.
- The location of publication was discussed with suggestions it should be on NHS Choices and NHS England websites.
- The creation of an index of all charity links was also suggested.
- Slide 9 needs to include the benefit of understanding the prevention of illnesses.

New action taken: Programme Team to finalise engagement summary document and publish once approval has been received. Programme Board members were asked to provide further feedback by e-mail as appropriate.

10 Project Validation Review

(Paper 07: 'Project Validation Review' v3.1 – amended version)



Outcome: Paper 7 was discussed and reviewed by the Board.

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AOB: None

11 Next Board Meeting

Monday 17 November 13.30-15.30

VC: Skipton House (6B6) and Quarry House (4W25)

12 Open Actions

From 25 June 2014 meeting:

1. **CLOSED** - Ask a clinical representative to become a member of the board (allocated to Tim Kelsey).
Martin McShane in Sir Bruce Keogh's absence now attending the Programme Board Sarah Schofield (Pathfinder CCG) will be in attendance from November.

2. **CLOSED** - 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). This action is being tracked via PVR.

From 16 July 2014 meeting:

3. 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. To be presented on 17 November 2014

From 26 August 2014 meeting:

4. Risk and issues log to be developed and presented to the Programme Board for baselining on 23 September 2014 (Allocated to Eve Roodhouse).
A full review is taking place on risks and issues. PB gave some further risks and issues to be incorporated into highlight report on 15 October 2014. Full risk and issues register to be presented to the Programme Board as per PVR action plan on 17 November 2014.
5. **CLOSED** - Gateway 0 review to be scheduled (allocated to Eve Roodhouse).
Programme Assurance Review has been agreed rather than Gateway 0 at the assessment meeting on 27 October 2014. The first meeting will occur on 14 January 2014 and the PAR will commence on 3-5 February 2015.
6. **CLOSED** - Available funding for care.data to be considered based on AW letter (allocated to Tim Kelsey).
Programme funding for care.data has now been agreed for 2014-2015.
7. Care.data to consider and present the outputs from pathfinders to the Programme Board (allocated to Eve Roodhouse).
Information analysis linked primary care to secondary care dataset presented and discussed with the board on 23 September 2014. Expert Reference Group held on 23 October 2014 work is being progressed and will be represented to the Programme Board.
8. **CLOSED** - Discuss the way in which the engagement report will be presented to the Advisory Group (allocated to Eve Roodhouse and Simon Denegri)
Engagement summary has been presented to the Advisory Group on 17 October 2014. They will provide feedback to ER direct prior to publication.

From 23 September 2014 meeting:

9. **CLOSED** - Pathfinder plan to be baselined and presented to the PB on 15 October 2014 (Allocated to Eve Roodhouse).
The Pathfinder plan was presented to the Board and approved on the 15 October.
10. An overview of care.data costs to be included in the Programme board highlight report (Allocated to Eve Roodhouse).
There is no business case in place; work is ongoing with HSCIC & NHS England to track all spends across the programme.
11. **CLOSED** - Summary table of key demographics and backgrounds for pathfinder CCG's to be circulated to PB members (for reference) (Allocated to Eve Roodhouse).
Sent by ER to Programme Board members.

12. Conversation to occur between Tim Kelsey and Beverley Matthews (NHS IQ) regarding back-up/fast follower areas (Allocated to Tim Kelsey).
13. **CLOSED** - A session with MM, JN, GL, ER and Programme team members to be organised to discuss the proposed analysis of the primary to secondary care link dataset (Allocated to Eve Roodhouse).
A care.data expert reference group facilitated by Richard Irvine took place on the 23rd October.
14. A programme level vision statement as part of the Strategic case to be developed and circulated to the PB members for comments and approval via correspondence (Allocated to Eve Roodhouse).
15. **CLOSED** - PB members to be more deeply involved during the initial writing of the business case. Two members to be identified and contacted direct. (Allocated to Eve Roodhouse).
Eva Simmonds had conversations with several Programme Board members.
16. GL to look at Other national enterprises which share data from which we could learn, including overseas and outside health arena to be considered and findings discussed with ES (allocated to Geraint Lewis)
17. **CLOSED** - Updated proposed documents for publication to be circulated. PB members to approve for prior to being released in the public domain (Allocated to Eve Roodhouse).
Documents published on 7 October 2014
18. **CLOSED** - Success criteria document to be updated to reflect discussion by 15 October 2014 (Allocated to Eve Roodhouse).
Assurance, approvals and evaluation document joins this and other documents together.

From 15 October 2014 meeting:

19. **CLOSED** - Objection wording as approved by S of S for testing with pathfinders to be circulated to Programme Board members. (allocated to Eve Roodhouse)

Wording provided here:

Information about your health and care can help to improve NHS services for all patients. For example, it can help the NHS to improve early diagnosis and treatment of illnesses, including cancer and heart disease. It can also help the NHS to check that health and social care services are doing a good job, to provide the right services at the right time and to support researchers to develop new medicines and treatments.

To achieve these benefits for everyone, the health and social care system is planning to make better use of this information.

You have the right to opt out of allowing information about you to be used in this way. If you do not want your information to leave your GP practice please tell the practice that you wish to 'opt out'. Opting out will not in any way affect the care or treatment you receive as a patient.

We remain absolutely committed to keeping your data safe and secure and will take every step to protect your confidentiality. We will put strict controls around access to the data so that it is only used for the benefit of health and care services.

Discover more at.....

20. **CLOSED** - CPRD to share findings related to objection codes. (Allocated to CPRD)
Jon Ford discussing findings as an agenda item at the Programme Board on 17/11/2014.
21. DH to issue guidance as to when the Opt out would or would not apply and write to all ALBS.

(Allocated to DH)

22. **CLOSED** - Risk of adverse media coverage to be added to the list of risks and issues.
(Allocated to Eve Roodhouse)
Highlight report now reflects this action
23. **CLOSED** - Risk numbers 1 and 7 to drop out of top 5 risks. (Allocated to Eve Roodhouse)
Highlight report now reflects this action
24. Programme team to take GB through the test plan. (Allocated to David Ibbotson)
25. **CLOSED** - Assurance, approval & evaluation for pathfinders paper requires updates prior to approval by board. (Allocated to Eve Roodhouse)
To be presented to Programme Board on 17/11/2014
26. Programme Team to finalise engagement summary document and publish once approval has been received. Programme Board members to provide further feedback by e-mail as appropriate. (Allocated to Eve Roodhouse)