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care.data
Programme Board

Monday 17 November 2014

13:30 – 15:30

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

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MINUTES

Attendees:

Alan Barcroft	Research and Development, Department of Health
Graham Binns	Monitor
Jon Ford	MHRA on behalf of Ian Hudson
Bethan George	Deputy Director Integrated Care WELC Integrated Care Programme Tower Hamlets CCG
David Knight	Information Strategy, Department of Health
Dr Geraint Lewis	Chief Data Officer, NHS England
Martin McShane	Medical Director LTCs, on Behalf of Sir Bruce Keogh
Ronan O'Connor	Interim Director of Intelligence, Patients and Information Directorate NHS England (Chair)
Eve Roodhouse	Care.data Programme Director
Sarah Schofield	GP and Chair West Hampshire CCG
Eva Simmonds	Programme Manager, Health & Social Care Information Centre
Tom Ward	Care Quality Commission

Apologies:

Will Cavendish	Director General, Innovation, Growth and Technology, DH
Mark Davies	Informatics and Digital Strategy, Department of Health
Simon Denegri	National Institute for Health Research
Ciaran Devane	Chair of the care.data Advisory Group
Dr Ian Hudson	CEO, MHRA
Tim Kelsey	Care.data Senior Responsible Owner (SRO)
Sir Bruce Keogh	National Medical Director
Peter Knight	Deputy Director R&D, Head of Research, Information and Intelligence, DH
Prof John Newton	Chief Knowledge Officer, Public Health England
Neil Stutchbury	Monitor
Andy Williams	CEO, Health & Social Care Information Centre

Secretariat:

Donna Braisby	Care.data Programme Manager (Programme Controls)
████████	Care.data Programme Support Office

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1	**Welcome, introductions and apologies**
	Ronan O'Connor (RO) chaired the meeting on behalf of Tim Kelsey (TK). Sarah Schofield (GP and Chair West Hampshire CCG) was welcomed as a new member of the Programme Board. Apologies were noted.
2	**Agenda overview and requests for AOB**
	RO provided an overview of the agenda.
3	**Acceptance of minutes from last meeting and review of actions** (Paper 01: 'Programme Board Minutes 20141015' – *for approval)*
	The Programme Board minutes from 15 October 2014 were accepted as an accurate reflection of the meeting.

	Open actions from previous meetings were reviewed and updates were provided:
	• Actions from 16 July 2014
	  ○ Action 3 - The Business Case timelines are to be presented to the Board members during the meeting (agenda item 7). Action closed.
	• Actions from26 August 2014
	  ○ Action 4 - The full risk and issues register to be discussed during the meeting (agenda item 4) – to be carried forward.
	  ○ Action 7 – An Expert Reference Group has been formed which will progress the outputs of analysis from pathfinders. Terms of reference for the group will be presented to the Advisory Group on 19 November 2014 and following comments will be circulated to the Programme Board for approval via correspondence. The members supported the establishment of this group. Action closed.
	• Actions from 23 September 2014
	  ○ Action 10 – Work across NHS England and HSCIC is ongoing relating to the finances of care.data. The highlight report for December 2014 will include this information – to be carried forward
	  ○ Action 12 – Fast followers conversation between Tim Kelsey (TK) and Beverley Matthews - to be carried forward
	  ○ Action 14 -The programme level vision statement to be circulated to the PB members as part of the Programme Business Case on 15 December 2014 – to be carried forward.
	  ○ Action 16 - Other national enterprises which share data from which we could learn, including overseas and outside health arena is being considered – to be carried forward.
	• Actions from 15 October 2014
	  ○ Action 21 - Guidance to be issued relating to the opt-out applying by DH to be carried forward.
	  ○ Action 24 – Meeting being scheduled to take Graham Binns through the test plan, expected to be completed prior to the next Programme Board – to be carried forward.
	  ○ Action 26 – The engagement summary and next steps document is expected to be published prior to the next Programme Board after the appropriate approvals process has been completed – to be carried forward.

	Outcome: The minutes from the board meeting held on 15 October were accepted as submitted.
4	**Programme Status update** (Paper 02: 'Programme Board Highlight Report 20141117– *for information and discussion*)
	Overall delivery confidence commentary
	Eve Roodhouse (ER) raised the following points: • The Health Select Committee has invited the SRO to give evidence to them alongside Dame Fiona Caldicott (National Data Guardian). A date is yet to be scheduled however this is

- expected to take place no earlier than December 2014.
- The Programme Business case is to be presented to the Board during the 15 December 2014 meeting for engagement, feedback, and endorsement. An update to be provided in agenda item 7.
- Programme Board approval to commence fair processing and subsequent extraction will be sought from the board in January 2015. HSCIC board needs to confirm readiness to proceed in advance as joint data controller with NHS England. Care.data will be discussed at HSCIC Board meetings in December 2014 and January 2015, January being a public session.
- Communications are scheduled to start with the public in February 2015. Several risks related to the readiness of the data management environment are being managed in the HSCIC and Andy Williams (AW) has sought assurance on the delivery timelines which remain ambitious but achievable.
- IIGOP will host its first meeting with the Advisory Group members on the 19 November, following the Advisory Group session. Following the appointment of Dame Fiona as National Data Guardian discussions are underway with IIGOP to ensure any implications are understood.
- FAQs and communication materials have been issued to CCGs for initial review, the deadline for feedback is week commencing 17 November. An editorial review panel has been established to capture and make amendments as agreed.
- A Programme Assurance Review will take place (instead of a Gateway 0 review) from 3 - 5 February 2015.

Stakeholder engagement and media

- The Engagement Summary and Next step documents (Formerly "You Said, We Did") is expected to be published in the near future once clearance is received from DH/Ministers.
- A public session hosted by the Advisory Group is scheduled for 26 November 2014 in Manchester which is fully booked. Members of the programme team are attending to support this session.
- Sarah Schofield discussed the first locality meeting in West Hampshire (which had taken place the previous week). Initially attendees were sceptical, however by the end of the session they were enthusiastic and keen to sign up. She added the first public engagement meeting had been scheduled. The GPs were concerned by the level of burden, however were surprised to discover Hospital Episode Statistic (HES) data has been extracted and held for years and they found this very reassuring.

Commissioning strategy and policy

- There remain some detailed points to resolve in terms of the communication and implementation of the opt-out. The programme team is working these through with colleagues from DH, HSCIC and IIGOP. They will then inform guidance for GPs and FAQs for the public.

HSCIC Strategic Capability Platform

- ER stated that the Strategic Capability Platform scope and vision was at a discovery stage, the HSCIC will corporately determine more precisely how we will proceed in the long term.

Secure Data Facility (SDF)
- The plans around the SDF are progressing well and a phased approach is being adopted, with the pathfinder stage providing an opportunity to test and evaluate the provision of such a service by the HSCIC.
- Tom Ward (TW) asked what the physical aspect of the SDF is. ER responded it will be a secure room in Leeds from which no data can leave from in the pathfinder stage.
- ER asked if the Programme Board supported the continuation of the Expert Reference Group, which was confirmed.
- The Terms of Reference needs to be circulated to the PB after comments have been received from the Advisory Group and impacted for their approval.

Risks and issues

(Papers 03a & 03b: "Risk Registers 20141117"- *for baselining*)

- ER stated that risks related to resources for care.data had been removed from the top 5 risks and issues in the risks log as discussed during the previous meeting. Additional resources will continue to join the programme team between December 2014 and March 2015.
- The risk and issue logs (papers 03a & 03b) have been withdrawn from this meeting as a further iteration is required by the programme team prior to submission to the Programme Board. ER noted there are three levels of risks and issues in the programme, those raised to the members in the highlight report, programme level recorded on the databases, and those managed at project level.
- ER confirmed that funding issues had been addressed for financial year 2014-2015 with NHS England as the primary funding organization. Business planning is underway at NHS England and HSCIC to secure funding for 2015-2016 and the Programme Business Case will further support this.

(Paper 04: "Final Summary Engagement and Next Steps Document 20141117"- *for information*)
- No comments were received from the Programme Board members.

Outcome: The highlight report was discussed and reviewed by the Programme Board.

New action taken: Programme team to circulate the ToR for the Expert Reference Group to the PB members once changes have been impacted from the Advisory Group.

5 | **Improving transparency of care.data**
(Paper 05: "Proposal on transparency and publication of care.data Programme Board papers 20141117- *for approval*)

- Donna Braisby (DB) introduced the paper, raising the fact that the programme needed to improve transparency.
- Programme Board members agreed the proposal to publish Minutes, Agenda and papers (once finalised) going forwards.
- Papers will be published in the following order:
  o Programme Board agenda from November and minutes from October will first be released and published as soon as the website was available.
  o Programme Board agendas and minutes from June – September 2014 will be published before the next board meeting on 15 December 2014.
  o Papers for the meetings from January to May 2014 will be published once previous Board members are informed.
  o Papers which are presented will be published once they have been finalised and approved by the Programme Board.

New action taken: Programme Board papers to be published as per agreement and proposal.

Outcome: Proposal on transparency and publication of care.data Programme Board papers agreed.

6 | **Updated Assurance, Approval and Evaluation for Pathfinders**
(Paper 06: 'Assurance, Approval and Evaluation for Pathfinders 20141117' – *for approval)*

- Geraint Lewis (GL) suggested having a flowchart of approvals included in the Assurance, Approvals & Evaluation for Pathfinders document to supplement table B to ease the reading of the document.
- ER agreed to reflect any agreement made with Dame Fiona Caldicott and Richard Wild following appointment as National Data Guardian.

New action taken: Further amendments to be made to the assurance, approval and evaluation for pathfinders document to be amended to reflect the comments of the Programme Board.

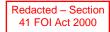|	
7	**Business Case update** (Presentation Paper 07: 'Creative Approach Presentation 20141117' – *for update)* An update was provided by ER and Eva Simmonds (ES), regarding timelines, datasets, key milestones and an options framework. Extensive comments were provided from the Board. - The Programme Business Case (PBC) is to be circulated to the members in advance of the 15 December 2014. ER asked for names of individuals from each organisation who would like to review the document. - Mapping datasets to key priorities was discussed in depth. GL asked how the totals scores were established. It was explained the breadth of score multiplied by the complexity and cost of the dataset established the total score. - TW added there was no scoring regarding the completeness of the data. - SS had concerns over the pathology dataset as the way in which GPs work with pathology laboratories could lead to only part of the information being gathered. - Martin McShane (MM) suggested the benefits of the datasets should be considered. ER added that once the datasets had been decided detailed benefits work would commence. - Bethan George (BG) said the ONS mortality data needed to be included. - A discussion took place regarding which datasets should be included in the PBC based on the information presented. It was agreed that a session should be scheduled through NIB to discuss further. It was noted that the PB should have a 'bucket fund' to use as the programme progresses as the priorities may change over the years. - The options framework was discussed by the members and several changes were made to the options which ES will take forward to make amendments - New action taken: ES to set up a session (or sessions) through the National Information Board to discuss which datasets to take forward in the Programme Business Case.
8	**Project Validation Review** (Paper 08: "Project Validation Review" - *for update*) ER highlighted that the program team were focused on closing down activity relating to recommendation 5 (financial spend control process) and recommendation 6 (risks and issues). Redacted – Section 36 FOI Act 2000
9	**AOB:** - DK made a request to explore how the work we are doing for care.data would support fair processing for CSUs/commissioners. **New action taken: ER to follow up with RO, TK and DK to explore how the work we are doing for care.data would support fair processing for CSUs/commissioners.** **Expert Reference Group** - The expert reference group was discussed as part of the programme status update (agenda item number 4) **Analysis of Objection Codes** Redacted – Section 41 FOI Act 2000

10	**Next Board Meeting**
	Monday 15 December 13.00-15.00
	VC: Skipton House (6B6) and Quarry House (4W25)

11	**Open Actions**

From 26 August 2014 meeting:

1. Risk and issues log to be developed and presented to the Programme Board for baselining on 23 September 2014 (*Allocated to Eve Roodhouse*).
   Expected to be presented 15 December 2014 as per notes above.

From 23 September 2014 meeting:

2. 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 expected to be presented in the highlight report 15 December 2014.

3. Conversation to occur between Tim Kelsey and Beverley Matthews (NHS IQ) regarding back-up/fast follower areas (*Allocated to Tim Kelsey*).

4. 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*).
   The programme level vision statement will be included as part of the Programme Business Case, expected to be presented 15 December 2014.

5. 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*)

From 15 October 2014 meeting:

6. *DH to issue guidance as to when the Opt out would or would not apply and write to all ALBS. (Allocated to DH)*

7. Programme team to take GB through the test plan. *(Allocated to David Ibbotson).**The programme team is scheduling a meeting, expected to be completed by 15 December 2014.*

8. Assurance, approval & evaluation for pathfinders paper requires updates prior to approval by board. (Allocated to Eve Roodhouse)
   Further amendments to be made following presentation to Programme Board on 17/11/2014. To be resubmitted on 15 December 2014.

9. *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)*

The engagement summary and next steps document is expected to be published prior to the next Programme Board on 15 December 2014 after the appropriate approvals process has been completed.

From 17 November 2014

10. Programme team to circulate the ToR for the Expert Reference Group to the PB members once changes have been impacted from the Advisory Group. *(Allocated to Donna Braisby).*

11. Programme Board papers to be published as per agreement and proposal. *(Allocated to Donna Braisby).*

12. A session to be scheduled with the National Information Board to discuss which datasets to take forward in the Programme Business Case. *(Allocated to Eva Simmonds)*

13. Explore how the work we are doing for care.data would support fair processing for CSUs/commissioners. *(Allocated to Eve Roodhouse, Ronan O'Connor, and David Knight)*