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care.data
Programme Board

Wednesday 25th June 2014
10:30 – 12:30
Skipton House, London

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MINUTES

Attendees:

Tim Kelsey	Care.data Senior Responsible Owner (SRO)
Eve Roodhouse	Care.data Programme Director
Peter Knight	Deputy Director R&D, Head of Research Information & Intelligence, DH
Graham Binns	Monitor (on behalf of Neil Stutchbury)
Will Cavendish	Director General - Innovation, Growth and Technology, DH
Dr Geraint Lewis	Chief Data Officer, NHS England
John Parkinson	MHRA (on behalf of Dr Ian Hudson)
Prof John Newton	Chief Knowledge Officer, Public Health England

Apologies:

Dr Ian Hudson	CEO, MHRA
Neil Stutchbury	Monitor
Simon Denegri	National Institute for Health Research

Response to Membership Invite Pending:

Tom Ward	Care Quality Commission
Sir Bruce Keogh	National Medical Director, NHS England

Secretariat:

David Farrell	care.data Programme Team

1	**Welcome, introductions and apologies**

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

He explained that this was the first meeting of the reconvened programme board with a revised membership and Terms of Reference (ToR) and also explained the background to this, i.e. in response to one of the key recommendations from the recent Major Projects Authority (MPA) Project Validation Review (PVR) the programme board was stood down at the previous meeting in May. He also explained that there are a couple of outstanding responses to invitations to be members and that membership itself would be discussed at this meeting.

The board were informed that the intention is to meet monthly and indeed perhaps more frequently over the next few months to support the pathfinder stage. Additionally, there will be a need at times to ask for feedback/decisions/guidance through a correspondence route.

2	**Agenda overview and requests for AOB**

TK continued to provide an overview of the agenda. There were no requests for AOB at this point.

3	**Re-constitution of board / governance**

(Paper 01: 'care data Programme Board ToR DRAFT – *for approval*)

Key points relating to the ToR:
- The membership has been put together to bring expertise and also to ensure appropriate challenge is in place (the need for appropriate challenge was raised by the PVR).
- TK felt that the membership is missing a lay representative/voice and proposed that a post should be publically advertised. The need for such a role was challenged on the basis that the Advisory Group was felt to provide a forum for such representation.
- TK explained the overall governance and that the Advisory Group can make recommendations to the board. To strengthen this, it was therefore agreed that Ciaran Devane (the Chair of the Advisory Group) should be invited to be a member of the board (or to nominate someone from the Advisory Group to attend if he cannot) to provide lay representation (*update: an invite has subsequently gone out to Ciaran*).
- It was agreed that the Health & Social Care Information Centre (HSCIC) should be independently represented (although Eve Roodhouse (ER) is an HSCIC employee she is acting as Programme Director) and it was agreed that Andy Williams (HSCIC CEO) should be invited to be a member of the board (*update: an invite has subsequently gone out to Andy and he has accepted*).
- It was also agreed that TK should ask someone from the Clinical Advisory Group to attend (via Sir Bruce Keogh) (**New Action: 1**).
- The link to and role of the National Information Board (NIB) was discussed – the ToR for the NIB describes it further. It was agreed to include the diagram from the NIB ToR in this programme board ToR.
- TK explained that the role of Director of Intelligence in NHS England is being advertised – the intention is that they will become the SRO for care.data when appointed. WC queried whether the successful candidate would be a full time SRO and highlighted that he wanted to have a further separate discussion with TK (**New Action: 2**).
- The ToR needs to include specific mention of holding organisations to account for delivery (including 'constituent delivery organisations' such as Public Health England).
- The board needs to ensure that potential tensions are managed (particularly with other initiatives).
- Clarity to be added to the ToR regarding decision points (critical judgments at certain points).

	Outcome: ToR was approved (pending changes as per above).
	(Update: ToR updated and will be submitted to the board on 16th July as an approved baselined version).
	On a wider point, the board needs to consider an appropriate approach to communicating with previous member organisations/other stakeholder members (**New Action: 3**)
4	**Programme background, overview and key messages**
	TK talked through a number of key items:
	• A large number of stakeholder engagement events have taken place including recent NHS England Open House events – these was held over four different sites at the same time with key speakers/items projected across all the sites – the response was very positive.
	• The Advisory Group had just met (immediately before this programme board) and had provided feedback on the Pathfinder Proposals and Planning Principles (a sub-group of the Advisory Group had provided detailed feedback).
	• Additionally, the Information Commissioner's Office representative (Dawn Monaghan) had provided a good overview of fair processing requirements for the Advisory Group. The purpose of the Pathfinder stage is to enable them (GPs) to carry out/meet fair processing requirements.
	• The Independent Information Governance Oversight Panel (IIGOP, with Dame Fiona Caldicott as chair) will provide advice to the programme board to help support any decision to go ahead with the Pathfinder implementation and will also provide advice for the programme board, based upon agreed criteria, in relation to the success of the Pathfinder implementation to support any subsequent decision as regards further rollout.
	• The plan (the commitment of the programme) does not go beyond the Pathfinder stage at this time and it is expected that the business case for the programme will pick up additional/wider areas of the programme.
	• Data quality is a very strong offering for GPs, along with ensuring a level of benchmarking against QOF and also having data available for their clinical re-validation.
	• Around what we anticipate the data being used for, whilst we don't have to be prescriptive in detail (this is up to the Clinical Advisory Group), we need to be clear as to the general purposes of use (e.g. research purposes, public health uses).
5	**Board Highlight Report and PVR Recommendations**
	(Paper 02: 'care data Programme Board Highlight Report' – *for information*)
	(Paper 03: 'PVR Recommendations' – *for information*) Redacted – Section 36 FOI Act 2000
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6 & 7	**Planning principles; Pathfinder objectives and approach** (Paper 04: 'Planning Principles and FAQs' – *for approval*) (Paper 05: 'Care.data Pathfinder Proposal' – *for approval*) ER introduced the documents and explained that the planning principles are a set of statements of pre-requisites for extracting or releasing data. The board provided feedback for consideration and this will be incorporated in the documents. Key points of feedback from the programme board (and also Advisory Group who met immediately before this meeting were): - Suggest not use the name 'lab' ('secure lab') and use 'secure data facility' (or similar). - Needs to specify Public Health access to data. - Ensure alignment of the Pathfinder proposals to the planning principles document (this is about checking language etc). For example, we shouldn't use the term 'go/no-go' in relation to decision points. - Draw out the research connection more. Be clear that we are doing research, when and how it will play into the Pathfinder stage. - Make it clear that we wish to assess burden on the GP/practice as part of the pathfinder stage. - Data Quality (DQ) should be part of the pathfinder stage i.e. will the GP Practice get a DQ report on the data they submit? What DQ reports will we create once linked? How will this be part of Pathfinder? - Be explicit about ICO involvement in pathfinder stage – to explain how the testing of guidance to GP practices might be part of this process. - Be clear that the Pathfinder stage will also test national materials i.e. the fair processing pages provided by HSCIC as this is a part of the whole fair processing package. The ICO is clear that there are layers of fair processing, national, regional and local (specific to the GP practice). - Need to be clear how we will get a representative sample. - Pathfinder selection should consider inclusion of those who are far down the route for other initiatives such as Summary Care Record. - Make explicit reference to the Secretary of State needing to sign off wording/approach to objections in the planning principles document. **Outcome: The planning principles and pathfinder approach were approved (pending changes specified) and the board were happy for the programme to move forward to pathfinder recruitment.** *(Update: Documents updated and will be submitted to the board on 16th July as approved baselined versions).*
8	**AOB** No AOB.

Next Board meeting

(Anticipated)

Tuesday 26th August 2014: 1.30 – 3.30 (diary invite to follow)

Actions

1. Ask someone from the Clinical Advisory Group to become a member of the board (via Sir Bruce Keogh).
   (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*)