

care.data
Programme Board

Tuesday 23 September 2014

11:30 – 13.30

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
Graham Binns	Monitor
Tom Ward	Care Quality Commission
Martin McShane	National Medical Director
David Knight	Department of Health
Alan Barcroft	Department of Health
Jon Ford	MHRA

Apologies:

Andy Williams	CEO, Health & Social Care Information Centre
Dr Ian Hudson	CEO, Medicines and Healthcare products Regulatory Agency (MHRA)
Ciaran Devane	Chair of the care.data Advisory Group
Peter Knight	Deputy Director R&D, Head of Research Information & Intelligence, DH
Will Cavendish	Director General - Innovation, Growth and Technology, DH
Bethan George	Deputy Director Integrated Care WELC Integrated Care Program Tower Hamlets CCG
Sir Bruce Keogh	National Medical Director
Neil Stutchbury	Monitor
Simon Denegri	National Institute for Health Research

Secretariat:

Donna Braisy	care.data Programme Manager (Controls and Governance)
[REDACTED]	care.data Programme Support Office

Redacted – Section
40 FOI Act 2000

1	<p><u>Welcome, introductions and apologies</u></p> <p>Tim Kelsey (TK) welcomed members and noted apologies received.</p> <ul style="list-style-type: none"> • Sir Bruce Keogh's office confirmed he will attend the care.data Programme Board where his availability will allow, and in his absence Martin McShane will attend as his deputy.
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></p> <p>(Paper 01: 'Programme Board Minutes 20140826' – <i>for acceptance</i>)</p> <p><u>Amendments to Minutes</u></p> <ul style="list-style-type: none"> • Page 4; section 6 Roadmap – Primary care dataset, Outcome 2 addition of 'However, we will continue to engage with interested stakeholders in advance of consultation.' • Page 6, section 13 Open Actions, point 1 – Amended to read 'Ask a clinical representative to become a member of the board' <p><u>Open actions</u></p> <ul style="list-style-type: none"> • TK suggested increasing the clinical representation on the Programme Board (PB) to include someone from a pathfinder area. Eve Roodhouse (ER) stated that an informal approach was being made in the first instance. Name would be provided once confirmation received. • ER confirmed that Ciaran Devane would be chairing the Advisory Group until January 2015. • TK will meet Andy Williams (AW) to further discuss and consider possible funding for the programme, prior to the next PB on 15 October 2014. <p>Outcome: The minutes from the board meeting held on 26 August were accepted as submitted once amendments made.</p>
4	<p><u>Board highlight report and plan</u></p> <p>(Paper 02: 'Programme Board Highlight Report' – <i>for information</i>)</p> <p><u>Overall Delivery confidence commentary</u></p> <ul style="list-style-type: none"> • ER stated that further detailed planning with CCGs, Ipsos MORI and the creative agency gave cause to review the plan, including the critical path. Detailed planning is expected to be concluded and the plan be baselined for presentation to the board on 15 October 2014. • The Business Case for the programme is being developed and a Business Case Specialist (Stefan Sanchez) officially started to assist in this area on the 22nd September. The programme team are confident relating to timelines taking the business case forward. • Business critical positions have been financially authorized by the HSCIC Director of Information and Analytics. Progress is now being made for advertisement of these posts. Joiners are expected to be in place between November - January. This is however leaving some areas in a difficult position until the resources are in place. <p>New action taken: Pathfinder plan to be baselined and presented to the PB on 15 October 2014.</p> <p><u>Communications, Stakeholder engagement and Media</u></p> <ul style="list-style-type: none"> • On 15 and 16 September, the public focus groups were presented a basic stimulus material to test creative proposition. One material was preferred over the others during these sessions, providing a clear steer to the programme team. • An HSJ round table on care.data took place in September, which TK attended as a participant. An article from that session is scheduled to be published on 24 October.

- TK asked for Sam Lister to be involved as part of the development of the handling plan for pathfinder announcement.
- The Advisory Group engagement meeting which took place the 6 September in London went well. A further session is to be planned in January 2015 in a pathfinder area.

Commissioning Strategy and Policy



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FOI Act 2000

- Work on the legal directions and joint data controller agreement between NHS England and HSCIC is being progressed

Technical and Service Readiness

- ER stated that work on SDF (Secure Data Facility) is progressing well. She clarified that HSCIC are proactively seeking feedback on customer requirements for secure data access whilst in parallel developing an early 'reading room' facility, which, in the first instance will be used for the pathfinder stage of care.data but will also be used for other purposes.

Graham Binns (GB) asked if there is now a technical design in place that is useable for pathfinders. ER stated that the primary care data will now be landed on the existing Data Management Environment (DME) as discussed at the last board and that the technical designs, along with the plans are being reviewed in detail and finalised in line with the detailed planning ongoing with CCGs. Detailed planning is flushing out all the risks and issues which are also being carefully documented. Revised plan will be presented to the board on 15 October as noted above.

Risks and issues

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

- David Knight (DK) stated that media attention could adversely impact public perception.
- Jon Newton (JN) raised the risk that the programme scope could be constrained too far in response to key stakeholders, thus reducing the value of the data.
- Geraint Lewis (GL) raised the risk of the upcoming general election and entering the Purdah period, given the pathfinder and business case timeframes.
- TK identified the future source of funding for fair processing has not been identified yet. The price for fair processing needs to be the most cost effective method whilst maximizing the value of fair processing.
- GL expressed concern that the focus is on primary care to secondary care linked data. However the future of the programme should involve the introduction of other datasets. ER assured the board that the process of developing the business case will help ensure a focus on the strategic direction of the programme as well as on the development of the primary care to secondary care linked data. MK also emphasised how important it was to establish the primary care dataset referring to it as 'the north sea oil' and therefore supported the focus on this area.
- DK queried the availability of finance for the pathfinder stage. TK outlined that the programme was funded by NHS England but that funding for the creation of the platform for extraction tool and for storage of extracted data needed to be identified quickly.
- GL asked for clarity on the funding for the financial year 2014 – 2015. TK assured the board that this issue would be resolved in the immediate future; however there is no risk that the funding will not be available.
- GL also asked for a funding report to be designed in order to track funding. ER confirmed this is clear and in place for HSCIC however in order to gain a full oversight of NHS England costs a meeting had been scheduled with Wes Dale. TK asked an overview of care.data costs to be produced for the next Programme Board.

New action taken: An overview of care.data costs to be included in the Highlight report

5	<p><u>Outcome of the Pathfinder Selection Panel</u></p> <p>(Paper 03: 'Care.data Pathfinder Selection Panel notes' – <i>for endorsement</i>)</p> <ul style="list-style-type: none"> ER summarised the discussions with the selection panel which took place on the 27 August and 9 September. She confirmed that 4 CCGs (Leeds [collaboration across 3 CCGs - Leeds North, West and South East], Blackburn with Darwen, West Hampshire and Somerset) were proposed to be taken forward as pathfinder areas and asked for the endorsement of the board. ER highlighted the fact that those CCGs had different key demographics and backgrounds, GP systems and represented different challenges. She stated that 2 other CCGs had also expressed an interest in becoming pathfinders. A discussion took place that they could be considered as fast followers post pathfinders. It was requested the summary table for the CCGs to be circulated to the PB. Martin McShane (MM) stated that areas involved in the Long Term Conditions programme (LTC) in Somerset should be considered as a back-up or fast followers. He raised concern that if CCGs haven't been accepted as pathfinders the decision based on demographics should be communicated. <p>New action taken: Programme secretariat to circulate summary table of key demographics and backgrounds for pathfinder CCG's to PB members (for reference).</p> <p>New action taken: TK to speak to Beverley Matthews (NHS IQ) regarding back-up/fast follower areas.</p> <p>Outcome: the selection of CCGs by the panel has been endorsed by the Programme Board</p>
6	<p><u>Proposed early analysis of the primary to secondary care link dataset</u></p> <p>(Paper 04: "Information analysis primary care-secondary care dataset" -<i>for discussion</i>)</p> <ul style="list-style-type: none"> The board commented that the paper was very helpful and it generated some good discussion. ER explained that the approach had been designed to link with the benefits as described in the original GPES IAG application. ER stated that HSCIC analysts will be working alongside NHS England to develop a complementary analysis plan focusing on data quality. MM stated that the way data set values are tracked needs to be improved and indicators need to be better tracked. Furthermore he stated the value on interventions being delivered over the absence of interventions not being delivered needs to be communicated. Interestingly in areas where there has been an increase in dementia rates hospital admissions have fallen. JN asked if the Healthcheck programme would show whether it has resulted in a reduction in admissions. GL stated care.data needed to show three areas: 1. The data does something useful, 2. Provides a hunger for data, 3. The data does something useful for GPs. The Board were interested in how they could help develop the analysis work further. ER asked for PB members to be involved in a session alongside the programme team to progress the initial analysis from pathfinder areas. MM, JN, GL agreed to participate. <p>New action taken: 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 linked dataset.</p>
7	<p><u>Business Case discussion</u></p> <p>(Presentation tabled on the day-<i>for discussion</i>)</p>

	<p>Eva Simmonds (ES) provided a summary of the Business Case updates, vision and next steps:</p> <ul style="list-style-type: none"> • Further to the business case vision and scope session which took place on the 17 September, ES and Stefan Sanchez (SS) have a clear idea of how it will be developed. • The approach for the inclusion of the SCP (Strategic capability platform) had been agreed with HSCIC senior stakeholders. • ES suggested that following the discussion at the vision and scope session regarding how to frame the vision of the programme, the business case might usefully demonstrate how the care.data programme is enabling the delivery of a wider, over-arching vision. • TK stated that the NIB (National Information Board) vision/strategy is currently under development and should be signed off in November 2014 and that a clear finished vision should be published by the end of November. This could provide the over-arching strategy for care.data. This approach was accepted, but board members did request further consideration is given to a programme level vision in addition to the over-arching approach. • ES noted that the Strategic Case is under development. A key area requiring input from board members will be the spending objectives. It was agreed that ES should contact board members individually to determine who could support the development of the spending objectives and strategic case. • TK noted that a report commissioned by NHS England and written by McKinsey and would provide useful input to the business case. ES will follow up with relevant contacts to obtain the report. • TK stated that the investment for transparency and data sharing should appear in the Business Case. The National Pupil Database and the CPRD were mentioned by ER and TK as one of the best national enterprises who share data. TK asked GL to think about other efficient national enterprises which may help in this area. <p>New action taken: ES to develop a programme level vision statement as part of the Strategic Case development. Comments and approval to be sought from board members via correspondence.</p> <p>New action taken: ER requested for PB members to be more deeply involved during the initial writing of the business case. ES to identify and contact direct.</p> <p>New action taken: GL to look at other national enterprises which share data from which we could learn, including overseas and outside health arena and discuss findings with ES</p>
8	<p><u>Publication of care.data programme board papers</u></p> <p>Paper 05: "Planning principles"</p> <ul style="list-style-type: none"> • DK stated that the FAQs in the document could be confusing and should be removed before publication. • ER stated that this document would be updated and circulated to PB members for final approval before publishing. <p>Paper 06: "Pathfinder proposal"</p> <p>Paper 07: "Roadmap to extend the primary care dataset"</p> <p>New action taken: Secretariat to circulate the updated proposed documents for publication. PB members to approve for prior to being released in the public domain.</p>
9	<p><u>AOB</u></p> <p><i>The following document was submitted for discussion:</i></p>

	<p>Paper 11: "Care.data Pathfinder Stage: EARLY DRAFT Success criteria".</p> <ul style="list-style-type: none"> • Amendments were suggested to the paper <ul style="list-style-type: none"> ◦ Proposed Success criteria, Ref 2 <ul style="list-style-type: none"> ▪ all reference to citizens to be amended to use the term patients ▪ wording need to be specific to pathfinder areas ▪ The communications material needs to be clear that the purpose and nature of intended data sharing is beyond direct care ◦ Proposed Success Criteria, Ref 6 <ul style="list-style-type: none"> ▪ Specifics need to be agreed with IIGOP and Dame Fiona Caldicott • TK stated that a personalised communication to patients must be tested, including a letter and email. The pathfinder stage should highlight what patient preferences are in relation to the channel through which they receive the personalised communication. • In terms of proposed success criteria, TK suggested that we should test that GPs felt that they were able to do their job (in terms of fair processing) and that patients felt they were well informed. • TK advised that IIGOP and Dame Fiona Caldicott (as chair) will need to confirm they are satisfied with communications materials and approach before fair processing and extraction. • MM outlined the need to avoid data confusion between using data for commissioning and using data for information continuity for personal care. He emphasised the fact that patients should be told how their data is going to be used. • DK suggested media monitoring also needs to be considered. <p>New action taken: Success criteria document to be updated to reflect discussion by 15 October 2014</p>
10	<p><u>Next Board Meeting</u></p> <p>Tuesday 15 October 2014: 15.00– 17.00 VC: Skipton House (6B6) and Quarry House (4W25)</p>
11	<p><u>Open Actions</u></p> <p>From 25 June 2014 meeting:</p> <ol style="list-style-type: none"> 1. Ask a clinical representative to become a member of the board (<i>allocated to Tim Kelsey</i>). <i>Sir Bruce Keogh (or deputy – Martin McShane) attended on 23 September and expected to attend future meetings. To enhance the clinical representation once pathfinder areas have been announced an invitation will be issued to a clinician from a pathfinder area. Another clinician has been approached.</i> 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 (<i>allocated to Will Cavendish and Tim Kelsey</i>). <i>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)</i> 3. Board to consider an appropriate approach to communicating with previous member organisations/other stakeholder members (<i>allocated to Eve Roodhouse</i>). <i>care.data provide updates via NIB</i> <p>From 16 July 2014 meeting:</p> <ol style="list-style-type: none"> 4. 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

	<p>pathfinder extract commencement for the board (these will be followed subsequently by the success criteria that would be examined post-extract) (<i>allocated to Eve Roodhouse</i>).</p> <p><i>Pre-requisites/dependencies have been presented to the board. Draft proposal of success criteria presented to the board on 23 September. Further work to be completed and presented to the board on 15 October 2014.</i></p> <ol style="list-style-type: none"> 5. Provide a proposed timeline for the development and approval of the PBC for board information (<i>allocated to Eve Roodhouse</i>). <i>Milestones provided in pathfinder plan, however the board would like to see a specific timeline for the business case.</i> From 26 August 2014 meeting: <ol style="list-style-type: none"> 6. Ensure secure data facility (SDF) work being completed and what outputs will be available from pathfinders. (<i>allocated to Eve Roodhouse</i>) <i>SDF design, service management requirements and overall costs have been confirmed. Purchasing of SDF kit and required built activities will commence over the next reporting period.</i> 7. Risk and issues log to be developed and presented to the Programme Board for baselining on 23 September 2014 (<i>Allocated to Eve Roodhouse</i>). <i>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.</i> 8. Gateway 0 review to be scheduled (<i>allocated to Eve Roodhouse</i>). <i>Assessment review meeting for Gateway 0 is being scheduled and is expected to take place in October.</i> 9. Available funding for care.data to be considered based on AW letter (<i>allocated to Tim Kelsey</i>). <i>Programme funding is for care.data is expected to be agreed by 15 October. However other funding sources need to be defined for fair processing, the platform for extraction tool and storage of extracted data.</i> 10. Care.data to consider and present the outputs from pathfinders to the Programme Board (<i>allocated to Eve Roodhouse</i>). <i>Information analysis linked primary care to secondary care dataset presented and discussed with the board on 23 September 2014. Further work to be progressed and represented.</i> 11. Discuss the way in which the engagement report will be presented to the Advisory Group (<i>allocated to Eve Roodhouse and Simon Denegri</i>) <i>To be presented to the PB on 15 October.</i> From 23 September 2014 meeting: <ol style="list-style-type: none"> 12. Pathfinder plan to be baselined and presented to the PB on 15 October 2014 (<i>Allocated to Eve Roodhouse</i>). 13. An overview of care.data costs to be included in the Programme board highlight report (<i>Allocated to Eve Roodhouse</i>). 14. Summary table of key demographics and backgrounds for pathfinder CCG's to be circulated to PB members (for reference) (<i>Allocated to Eve Roodhouse</i>). 15. Conversation to occur between Tim Kelsey and Beverley Matthews (NHS IQ) regarding back-up/fast follower areas (<i>Allocated to Tim Kelsey</i>). 16. 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 (<i>Allocated to Eve Roodhouse</i>). 17. 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 (<i>Allocated to Eve Roodhouse</i>). 18. PB members to be more deeply involved during the initial writing of the business case. Two members to be identified and contacted direct. (<i>Allocated to Eve Roodhouse</i>). 19. GL to look at Other national enterprises which share data from which we could learn,
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	<p>including overseas and outside health arena to be considered and findings discussed with ES (<i>allocated to Geraint Lewis</i>)</p> <p>20. Updated proposed documents for publication to be circulated. PB members to approve for prior to being released in the public domain (<i>Allocated to Eve Roodhouse</i>).</p> <p>21. Success criteria document to be updated to reflect discussion by 15 October 2014 (<i>Allocated to Eve Roodhouse</i>).</p>
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