

care.data
Programme Board – Main Session

Tuesday 24 March 2015
15:30 – 17:30

Skipton House room 5A1 and Quarry House room 4W26

MINUTES

Attendees:

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| Graham Binns | Monitor |
| Alan Barcroft | Research and Development, Department of Health |
| Simon Denegri | National Institute for Health Research |
| Jon Ford | Head of Operations, Clinical Practice Research Datalink |
| David Knight | Information Strategy, Department of Health |
| Martin McShane | Director (Domain 2) on Behalf of Sir Bruce Keogh |
| Ronan O'Connor | Director of Intelligence, Patients and Information Directorate |
| Eve Roodhouse | Care.data Programme Director |
| Sarah Schofield | GP and Chair of West Hampshire Clinical Commissioning Group |
| Neil Stutchbury | Knowledge Management Director, Monitor |
| Janet Valentine | Director for CPRD, MHRA |
| Tom Ward | Head of Intelligence and Information Management, Care Quality Commission |

Apologies:

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| Mark Davies | Informatics and Digital Strategy, Department of Health |
| Ciaran Devane | Chair of the care.data Advisory Group |
| Bethan George | Deputy Director Integrated Care WELC Integrated Care Program Tower Hamlets CCG |
| Dr Ian Hudson | CEO, Medicines and Healthcare Products Regulatory Agency |
| Tim Kelsey | Care.data Senior Responsible Owner (SRO) |
| Sir Bruce Keogh | National Medical Director, NHS England |
| Peter Knight | Deputy Director Research Contracting, Information Intelligence and Stakeholder Engagement, Department of Health |
| Dr Geraint Lewis | Chief Data Officer, NHS England |
| Prof John Newton | Chief Knowledge Officer, Public Health England |
| Andy Williams | CEO, Health & Social Care Information Centre |

Secretariat:

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| Donna Braisby | care.data Programme Manager, Health and Social Care Information Centre |
| Jade Thorpe | care.data Business Support Manager, Health and Social Care Information Centre |

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| 1. | <p><u>Welcome, introductions and apologies</u></p> <p>Ronan O'Connor (ROC) chaired the meeting on behalf of Tim Kelsey (TK). Apologies were noted.</p> |
| 2. | <p><u>Agenda overview and requests for AOB</u></p> <p>ROC provided an overview of the agenda. ROC advised that the care.data Programme Board papers from June – September 2014, and January onwards will not be published until after the election to ensure that the programme is compliant with pre-election guidelines.</p> |
| 3. | <p><u>Acceptance of minutes from last meeting and review of actions</u> (Paper 01: 'Programme Board Main Session Minutes 20150211' – <i>for approval</i>)</p> <p>The Programme Board minutes from 11 February 2015 were accepted as an accurate reflection of the meeting, with the following minor amendments to update member's titles.</p> <ul style="list-style-type: none"> • Alan Barcroft – Research and Development, Department of Health • Peter Knight – Deputy Director, Research Contracting, Information Intelligence and Stakeholder Engagement, Department of Health • Ronan O'Connor – Director of Intelligence, Patients and Information Directorate. <p>Open actions from previous meetings were reviewed and updates were provided:</p> <ul style="list-style-type: none"> • Actions from 23 September 2014 <ul style="list-style-type: none"> ○ Action 12 – Tim Kelsey advised the fast followers conversation needs to occur between Tim Kelsey (TK) and Ros Roughton. Eve Roodhouse (ER) to contact Ros now there is a clearer view - to be carried forward. • Actions from 15 December 2014 <ul style="list-style-type: none"> ○ Programme team to develop a Risk & Issue Assurance Framework. . A risk and issue assurance framework is in place, and will be updated alongside changes reflected in the Programme Assurance Review - CLOSED • Actions from 11 February 2015 <ul style="list-style-type: none"> ○ The Assurance, Approvals and Evaluation document to be updated and circulated via correspondence for final approval. Presented to the board on 24 March 2015 - CLOSED <p>Outcome: The minutes from the board meeting held on 11 February 2015 were approved as an accurate reflection.</p> |
| 4. | <p><u>Highlight Report</u> (Paper 02: 'Programme Highlight Report' – <i>for approval</i>)</p> <p>Eve Roodhouse (ER) presented the report.</p> <p><u>Overall Delivery</u></p> <p>Eve Roodhouse (ER) made the following additional points:</p> <ul style="list-style-type: none"> • The Programme Business Case (PBC) was discussed at the Informatics Portfolio Management Board IPMB meeting held on 26 February 2015, where direction of travel, scope and ambition were approved. Agreement was also given to proceed to development of the Outline Business Case for phase 1 (national rollout of the GP dataset) of the programme. • The Cabinet Office and HM Treasury will not officially receive the PBC until after the election. • Programme Board papers for October – December 2014 were published on 2 February 2015. <p><u>Communications, Stakeholder Engagement and Media</u></p> <ul style="list-style-type: none"> • The revised versions of all of the core communication materials have been circulated to Independent Information Governance Oversight Panel and the pathfinder teams for their review. • The SRO has agreed a request for an alternative creative approach from Somerset CCG. The creative agency has been briefed on this for the Somerset pathfinder and amendments to the public facing communication materials. |

Commissioning Strategy and Policy

- Confidentiality Advisory Group (CAG) regulations will set out the factors to which CAG must consider when advising the HSCIC on dissemination of data. These regulations will now not be laid in parliament before the election. This is a pre-requisite for data dissemination, as set out in the planning principles.
- Directions to the HSCIC in relation to opt-outs are being drafted by the Department of Health. An update on the timing for finalising the directions is being sought from the Department of Health.
- As the Privacy Impact Assessment is an NHS England document, it has proceeded through the NHS England gateway process. Publication is expected after the election.

Technology platform, extract systems and secure data facility

- The Secure Data Facility room has been built and the ICT equipment has now been installed, tested and assured by Solutions Assurance. The SDF use cases have now all been developed and the operational procedures are being developed as planned. The Security Officer is now in post.
- The extract system and data downloader is currently in the development and testing phase. The design of presenting data back within the data downloader has subsequently been challenged from an information governance and security perspective. A piece of work is being established that will consult with GP practices to review the requirements that may or may not lead to a change request.

Data Delivery

- Progress continues to be made confirming practice participation in the CCG areas. There are currently over 100 practices that have been confirmed as participating practices.
- Work has taken place to start to consider the options for the national rollout of the GP to HES linked dataset.

Data Access

- The Expert Reference Group meeting took place on 27 February 2015.

Outcome: The Highlight Report was discussed and reviewed by the Programme Board.

5. Assurance, Approvals and Evaluation

(Paper 03: Assurance, approvals and evaluation document 20150324 – for approval)

- ER advised that the document has now been updated with the amendments suggested by the programme board at the last meeting.
- Members agreed table A needs explicit reference to the Programme Board approving the core communication materials.
- The programme will work closely with the National Data Guardian and IIGOP before and during the testing of communications to ensure that the programme is well placed to meet the questions and conditions set out in the IIGOP report published on 18 December 2014.
- The Programme Board confirms they are content with the proposed evidence and associated documentation that will be provided to enable them to approve the start of testing the communications.

Outcome: The Assurance, Evaluation and Approvals document was approved subject to addition of PB approval of communication materials in table A.

6. Core Public Facing Communication Materials

(Paper 04: care.data Core Public Facing Communications Materials document 20150324 – for approval)

Phil Bastable (PB) attended to provide the programme board with the final versions of the core public facing communication materials for approval.

- PB explained that the core public facing communications have been developed to explain the way that the NHS shares data and the changes that are being introduced.
- PB advised that the materials have been through a series of reviews with CCGs and stakeholders. IIGOP have also discussed the materials at their meetings and provided feedback.

The following points about the paper were raised:

- There was an important discussion about the descriptive word ‘companies’ being used within the infographics document. Members queried whether or not this word should be used as it may be perceived incorrectly.
- After discussion members suggested it may be beneficial to continue to use the word ‘companies’ however include which companies these are i.e. pharmaceuticals companies etc.
- It was agreed that there needs to be excellent anticipatory communications in place with advocates who are well briefed to answer questions. ER advised that the Clinical Lead, Lisa Harrod-Rothwell, is currently working on this and is speaking with GPs within the pathfinder areas.
- The use of the statement ‘if you object your care will not be affected in any way’ was queried. ER advised that this was an area that had been explicitly discussed with both the Chief Medical Officer (Dame Sally Davies) and the National Data Guardian (Dame Fiona Caldicott) and a meeting was planned to ensure that views are aligned before the materials are finalised.
- ER advised that the previous iteration of materials did not have reference to type 2 within the opt-out information, as it was felt it was too difficult to explain. But due to feedback, this was then discussed with IIGOP who advised that reference to type 2 needed to be included, so it is now referenced within the information booklet. Members felt that this information was too complicated and should either be removed or be placed back within the FAQs.
- Members agreed that the communication materials have improved a great deal and are now very clear and articulated.
- Members agreed to delegate responsibility to the SRO for final sign off of the communication materials subject to working through the outstanding issue with CMO and National Data Guardian.

Outcome: The Core Public Facing Communications Materials delegated responsibility to the SRO for final sign off subject to working through the outstanding issue with CMO and National Data Guardian.

New Action: Members are asked to send any further comments in relation to the communication materials to Phil Bastable by Monday 30 March 2015.

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| 7. | <p><u>AOB</u> No further matters were raised for discussion.</p> | | | | | | | |
| 8. | <p><u>Next Board Meeting – Main Session</u> Wednesday 13 May 2015 10:00-12:00 VC: Skipton House (5A1) and Quarry House (4W26)</p> | | | | | | | |
| 9. | <p><u>Open Actions</u></p> <p>From 23 September 2014 meeting:</p> <table border="1" data-bbox="193 1377 1444 1512"> <tr> <td data-bbox="193 1377 247 1512">1</td> <td data-bbox="250 1377 1173 1512">Conversation to occur between Tim Kelsey and Beverley Matthews (NHS IQ) regarding back-up/fast follower areas ER to forward TK a note to progress with Roz Roughton of the CCG Assurance Team in NHS England.</td> <td data-bbox="1176 1377 1444 1512"><i>(Allocated to Tim Kelsey).</i></td> </tr> </table> <p>From 11 February 2015</p> <table border="1" data-bbox="193 1579 1444 1664"> <tr> <td data-bbox="193 1579 247 1664">2</td> <td data-bbox="250 1579 1173 1664">New Action: Members are asked to send any further comments in relation to the communication materials to Phil Bastable by Monday 30 March 2015.</td> <td data-bbox="1176 1579 1444 1664">Allocated to PB members.</td> </tr> </table> | | 1 | Conversation to occur between Tim Kelsey and Beverley Matthews (NHS IQ) regarding back-up/fast follower areas ER to forward TK a note to progress with Roz Roughton of the CCG Assurance Team in NHS England. | <i>(Allocated to Tim Kelsey).</i> | 2 | New Action: Members are asked to send any further comments in relation to the communication materials to Phil Bastable by Monday 30 March 2015. | Allocated to PB members. |
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