> **care.data**
> **Programme Board**

# Monday 31st March 2014
## 13:00 – 15:30
**VC: Quarry House, Leeds (1N14B); Skipton House, London (118D)**

# MINUTES

**Present:**

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| Tim Kelsey (Chair) | National Director for Patients and Information, NHS England, and care.data SRO |
| Alan Barcroft | Department of Health (DH) |
| Dr Martin Bardsley | Head of Research, Nuffield Trust |
| Chris Carrigan | Public Health England |
| David Farrell | Programme Manager, Health & Social Care Information Centre (HSCIC) (and secretariat) |
| Dr Jonathan Kay | Director of Clinical Informatics, NHS England |
| Dr Geraint Lewis | Chief Data Officer, NHS England |
| Ronan O'Connor | Regional Director for Patients and Information (South), NHS England |
| Eve Roodhouse | Programme Director for care.data, HSCIC |
| Neil Stutchbury | Monitor |
| Jeremy Thorp | Director of Business Architecture, HSCIC |
| Iain Wallen | NHS Trust Development Authority |
| Dr Tim Williams | Head of Research, Clinical Practice Research Datalink (CPRD) |

**Apologies:**

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| Martin Campbell | NHS England, SRO for the National Tariff System (NTS) programme |
| Peter Flynn | Head of Strategic Intelligence, NHS England |
| Dr Pete Green | NHS Medway (CCG representative) |
| Martin Hall | Health Education England |
| Peter Hall | External Relations Directorate, Department of Health (DH) |
| Max Jones | Director of Information and Data Services, HSCIC |
| Peter Knight | Deputy Director, Head of Research Information and Intelligence, Research & Development Directorate, DH – *Alan Barcroft deputised* |
| Alistair McDonald | NHS Business Services Authority |
| Richard Murray | Chief Analyst, NHS England |
| Prof John Newton | Chief Knowledge Officer Designate, Public Health England |
| Christine Outram | Director of Strategy & Intelligence, NHS England |
| John Parkinson | Clinical Practice Research Datalink (CPRD) – *Dr Tim Williams deputised* |
| Ming Tang | Director, Data and Information Management Systems, NHS England |
| Alexia Tonnel | NICE |
| Dr Jeremy Veillard | Vice-President, Research and Analysis, Canadian Institute for Health Information, University of Toronto |
| Tom Ward | Care Quality Commission |

**Distribution:**

As above, plus SRO Accountability Group membership
and

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| Karen Wheeler | Director General, Information and Group Operations Directorate, DH |

| 1 | **Introductions and apologies** |
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| | Eve Roodhouse (ER) was asked to chair the initial part of the meeting so welcomed members and noted apologies received. |
| | She also explained that Peter Knight (who Alan Barcroft was deputising for at this meeting) was about to change roles (from the Department of Health to the HSCIC). |
| **2** | **Agenda overview and requests for AOB** |
| | ER continued to provide an overview of the agenda and to ask for any requests for Any Other Business. |
| | Jeremy Thorp (JT) advised that he had a brief AOB item to include in relation to some customer research activity that the HSCIC are carrying out. |
| **3** | **Formal handover of SRO duties** |
| | ER explained that Chris Outram had passed over her SRO duties for the care.data programme to Tim Kelsey and she put this change forward to the board for their formal approval. |
| | **Outcome - The board formally approved the change of SRO and Tim Kelsey (TK) took over the chair.** |
| | TK provided some background/context to the change, explaining that this was driven by a need to revise the governance for the programme (this revised governance forms an agenda item later). |
| | He also explained that there is a need for a revisit of the Terms of Reference (ToR) and membership of the board in light of recent governance changes (including the establishment of an Advisory Group) and the need to ensure that the board operates in line with the ToR and has an appropriate membership that is not too large to enable it to operate effectively. |
| | **NEW BOARD ACTION (48):** <br> *It was noted that Department of Health (the External Relations Directorate; Alan Barcroft was attending on behalf of DH Research & Development) did not have any representation at the meeting – Eve Roodhouse to contact Peter Hall to ensure presence at future meetings (or an appropriate deputy) as a key member.* |
| **4** | **Acceptance of minutes from previous meeting** |
| | The minutes from the board meeting on 28th January 2014 were accepted as per the distributed paper. |
| **5 & 6** | **Key messages and update from the National Information Board** <br> **& Where we are…" the mood of the nation"** |
| | TK took both items together. In support of this item, papers providing an overview of media activity for the programme (timeline and channel graph) and useful links to a number of media articles had been distributed to the board in advance. |
| | Stakeholder feedback: |
| | He explained that the feedback from the wider system was that it was not clear as to what extracted data would be used for and also as to the governance around approval for this data for extraction and its uses. For care.data to work, it needs clear, transparent governance (both in relation to the data and also in relation to the programme itself) and clear, consistent messages behind it to inform. Also, the conversation as regards benefits has never really been had and key benefits not communicated. Additionally, it is apparent that, although rules and |

process have been followed in the past, what has been exposed is a less than viable programme of safeguards and assurance in places. Finally, many GPs have a less than perfect understanding of their role as data controller and this needs clarifying.

He went on to explain that, as a result of this and the public awareness extension, he and the team have spent a lot of time already with stakeholders driving out key issues; and a number of core themes have arisen:
1) there is a need for assurances and safeguards in regard to the use of data and access to this data (e.g. who can access? what security is in place?);
2) there is a need for robustness about the policy and the role of the HSCIC – not just from a safety viewpoint but also technical policy (e.g. pseudonymisation at source; the opt out process; making safe access to data available);
3) there is a need for increased GP support and awareness including information governance awareness support in the frontline of the NHS (in relation to handling confidential data) and support for GPs in what opt out means, as well as other issues such as what the benefits of the programme are (simple, clinical benefits in the short term to accompany longer term life science benefit);
4) there is need for appropriate levels of public information resources being available including accessibility of these resources for minority, disadvantaged and seldom-heard groups (this was raised particularly by bodies such as Healthwatch and voluntary groups);
5) there is a need for clarity as to the governance and process around data extraction and use including a clear view of the roles of the various committees (e.g. IAG, DAG) and their role in decision making.

Changes to legislation:

TK then went on to talk about the legislation changes. Primary changes mean that there will now be independent scrutiny of access to identifiable data and anonymised data has to be published by the HSCIC.
He explained that the role of this programme board will be to provide guidance and review for secondary legislation to ensure that it undergoes appropriate scrutiny levels.

**NEW BOARD ACTION (49):**
*Provide a briefing for the board in relation to the wording in the legislation around "commercial purposes".*

He went on to explain that the legislation provides a legal basis for patient opt out (not currently there).

Discussion followed as regards penalties for misuse of data in the changes to legislation and the 'one strike and out' rule for an organisation who misuses data. There is a need to consider the implications of this for organisations (this touches upon the potential, as has been discussed to provide safe 'fume cupboard' (secure data lab) environments for handling data which would alleviate the implications of this on organisations. In line with the potential of offering this, one of the roles for the board will be to support the HSCIC in becoming a high quality customer service centre.

National leaflet campaign (public understanding):

Although the (nationally dropped) leaflet was a focal point of a lot of feedback from the original public awareness campaign, TK explained that it does in fact seem to have gone out comprehensively (with a very small number of households not receiving it) and that, of those people who did receive it, on the whole it was reported to be helpful for those individuals surveyed. A recent BBC survey supported high levels of awareness however it was pointed out that awareness versus understanding the detail are different things.

6 Month Extension workstream *(note, now called the Phased Extension worksteam):*

TK then introduced Ronan O'Connor (RO'C), who is leading the '6 Month Extension' workstream (a task and finish group concentrating on activity through the public awareness

extension period).

RO'C briefly explained that his role includes the co-ordination of communications with an accompanying strategy based upon evidence based research/need. So this will include testing products, tools and resources and essentially asking what it is that people need (including GPs and patients). His main challenge is to get everyone in the same place, looking and talking to key stakeholders and groups.

He explained that it is important to get communications out as soon as possible and indeed he is planning to get an 'extension period activity' short communication out as soon as possible to all stakeholders; and this will be followed by a resource pack ('what is care.data?').

Board papers:

Whilst on the subject of communications, TK asked the board to agree the most appropriate way of ensuring that the key messages from this board are communicated appropriately and that the board is as transparent as possible. Indeed organisational boards such as NHS England and the HSCIC have public and private sessions and publish papers in line with these.

This was discussed amongst the members and it was agreed that, subsequent to the relaunch of the board with revised Terms of Reference, it would be a good idea to have private and public facing minutes for the board. The rationale for this is that, whilst most items discussed/decisions made should be transparent, there are some areas/items/papers that could be in draft form or commercially sensitive.

**NEW BOARD ACTION (50):**
*For programme boards following relaunch of the board with revised ToR, ensure private and public minutes are written and published.*

**NEW BOARD ACTION (51):**
*Martin Bardsley agreed to provide support with definition of criteria re what should be public and private in the board (including standing agenda items).*

ER provided a general update (key messages) from the HSCIC side.
She explained that, on the back of the recent Health Select Committee (Max Jones and Tim Kelsey appeared before the committee on 25th February to discuss care.data), a programme of work (predominantly Information Governance-related work and at an organisation level) has been established in the HSCIC to look at a number of things including the release of data / data sharing agreements.

Max Jones has been invited back to the Health Select Committee on 8th April and he will be attending with Kingsley Manning (HSCIC Chair). She explained that the subject area is specifically relating to the current situation concerning use/sharing of data (for example, HES data) and the lessons that might be learned for the future, so it is very much organisation rather than (care.data) programme level.

Jonathan Kay asked about the upcoming HSCIC audit report publications (as there are obvious communications implications and dependencies). TK explained that the first release (those relating to the 'new' HSCIC) was anticipated for April 3rd; and the second release (those relating to the 'old' IC) was anticipated for late May.

TK reiterated that the Secretary of State/government is in full support of this programme and that the decision to extend the public awareness period has received a positive response from stakeholders.

Martin Bardsley asked a question around the timetable for legislative changes and the level of risk this provides. RO'C explained that the programme team are currently waiting for a briefing paper from DH in regard to this.

**NEW BOARD ACTION (52):**

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| | *Eve Roodhouse to write a note to Peter Hall (on behalf of Tim Kelsey) to clarify the legislative timetable so risks and dependencies can be assessed in line with this.* |
| **7** | **Overview and review of revised governance and programme board ToR**<br><br>ER described the 3 papers in support of this item: the revised governance overview picture; the original programme governance document (previously approved by programme board); and the Terms of Reference (ToR) for the new Advisory Group. She also pointed out that the ToR for the Advisory Group was discussed at their first meeting, which took place on 24<sup>th</sup> February, and was subject to updates that were agreed at that meeting.<br><br>ER then talked through the governance picture, including what each of the workstreams does and what is involved in them. TK explained that he sees himself being in the SRO role for a short (rather than a long-term) period and he also made clear that the programme board is decision making board for the programme and is accountable to National Director for Patients & Information and the DH Informatics Accountable Officer (Karen Wheeler).<br><br>In response to a question in relation to the decision to extend the public awareness period and why this did not come through this programme board, TK acknowledged the point and said that, under revised governance this would not happen again in the future (and was linked to governance not being as clear as it should've been).<br><br>**NEW BOARD ACTION (53):**<br>*For clarity, the governance overview picture should show the links to the Secretary of State from the HSCIC Board and NHS England Board.*<br><br>**Outcome - The board formally approved the revised governance as presented with the minor change as noted in Action 53.**<br><br>TK went on to say that one of the most important governance graphics to construct is to reflect exactly what happens to GP data in the health service and who approves it (what the governance arrangements are) in the new environment. This is being put together for the Advisory Group and will be shared with the programme board when developed.<br><br>**NEW BOARD ACTION (54):**<br>*Provide the programme board with the picture reflecting what happens to GP data in the health service and who approves it (what the governance arrangements are) in the new environment.*<br><br>**NEW BOARD ACTION (55):**<br>*Send the Advisory Group membership and finalised Terms of Reference out to programme board members for information (the minutes are available via http://www.england.nhs.uk/ourwork/tsd/ad-grp/).*<br><br>Specific feedback from the programme board members on the draft Advisory Group ToR highlighted the need to review terminology for consistency (e.g. change to 'objection' instead of 'opt out').<br><br>A discussion followed as to the aims and appropriate ways of working (ToR) for the programme board. It was agreed that the board will need to work remotely or meet more regularly, particularly during this 6 month period. It was also agreed that the ToR should be more comprehensive and therefore should be redrawn for agreement by the board; and that the membership of the board itself should be revisited.<br><br>**NEW BOARD ACTION (56):**<br>*Rewrite the ToR for the programme board in the context of the original Programme Governance documentation and the revised (now agreed) governance. Provide this as a 'strawman' for the board (remotely).*<br>*The ToR should include public/private board sessions/agenda items with rules around what these are; when papers are required and what can be released; and lay membership. It should be explicit as regards membership of the board (i.e. why certain people are on the board). It* |

*should also consider principles such as maximum number of members and a quorum number.*

**NEW BOARD ACTION (57):**
*Change to 6-weekly programme board meetings with ad-hoc meetings where required (facility to call where necessary).*

**EXISTING ACTION (31) CLOSED:**
*Board members to suggest ideas/individual names to ensure local government and social care are fully represented as regards care.data:*
- *this is now being picked up via the governance review (including review of board ToR) – see Action 56 above.*

**EXISTING ACTION (37) CLOSED:**
*Agree appropriate patient representation for the care.data board:*
- *to be picked up as part of governance review (including review of board ToR) but public and patient groups now fully represented at the newly-established Advisory Group – see Action 56 above.*

**EXISTING ACTION (45) CLOSED:**
*Board to consider an appropriate external subject matter expert replacement for Mike Foster:*
- *to be picked up as part of governance review (including review of board ToR) but public and patient groups now fully represented at the newly-established Advisory Group – see Action 56 above.*

**8** | **Board Highlight Report**

ER explained that the format of the highlight report (which is a working document) has changed slightly to reflect the report used as an input for the SRO Accountability meetings. She then drew out key points from the report (including risks and issues), noting an increased optimism in the direction of travel and good progress having been made in planning, governance arrangements and the way in which NHS England and HSCIC teams were working together. She also shared the positive news that GPES (the GP Extract Service) is now working well for the QOF (Quality and Outcomes Framework) and talked around the strategic platform development work.

The board were introduced to the accompanying 'Plan on a Page', which is aimed at providing a quick, simple view of delivery through the next 9 month period (showing key activity and milestones). It was explained that this is still in draft/development (a working document) and that this version was provided for initial information.

The board asked, in relation to the Strategic Outline Case (SOC), that the approval process (route) is made available for them for clarity. Other queries relating to clarity of data access/use and the longer term timeline for data access/use resulted in additional actions.

**NEW BOARD ACTION (58):**
*Send out the approval process (in line with new governance arrangements) for the board's information.*

**NEW BOARD ACTION (59):**
*Check the specific agreement of data access/use as was agreed through the Advisory Group (IAG) ("for commissioning purposes") and report back to the board for clarity.*

**NEW BOARD ACTION (60):**
*Provide a 'roadmap' picture of future extractions of data within care.data (over next 2-3 years).*

**EXISTING ACTION (23) CLOSED:**
*Consultation with providers and key stakeholders to take place and report re clarity of requirements of the service (to use established groups for consultation). Approach/progress for this to be reported to board.*
- *Now being addressed through the 6 Month Extension workstream – update provided for this Board and updates and progress around this areas will be reported through the*

*reporting arrangements, including the board highlight report.*

**EXISTING ACTION (39) CLOSED:**
*Distribute the Strategic Outline Case (SOC) for programme board review and seek endorsement/approval from the programme board.*
- *As previous update, SOC still in development (progress been slower than anticipated due to resource constraints). Project Validation Review (PVR) assurance is being scheduled for the end of April. This will now be picked up via updates for this Board and updates and progress around this area will be reported through the reporting arrangements, including the board highlight report.*

| 9 | **Review of remaining open actions** |

The remaining open actions (those that had not been dealt with via previous agenda items) were reviewed.

**EXISTING ACTION (10) UPDATED:**
*Provide outputs from the Hospital Dataset consultation and subsequent approach/direction re Accelerators options for the board to consider:*
- *Resources have been reallocated to other (public awareness) activity in the recent period but the intention is to re-focus to move this forward.*

**EXISTING ACTION (29) CLOSED:**
*Re the proposed development 'Implantable Devices – adding a field to HES' - work through the practical details and ensure appropriate support and engagement in relation to it.*
- *Jeremy Thorp reported that this is now on the work list for the Standards for Care Information (SCCI) group and it will be picked up through that body. Agreed to close.*

**EXISTING ACTION (32) UPDATED:**
*Present the benefits approach, and collated benefits for care.data, to allow Board members to evaluate, comment and add to. This is likely to be early in 2014 to coincide with OBC development.*
- *A benefits approach has been developed (draft) with an initial benefits register and is being reviewed within the programme team. This will be submitted for board review.*

**EXISTING ACTION (43) UPDATED:**
*In relation to the proposed charging model produce a paper (i.e. informed impact assessment, responsibilities, options, recommendations) for consideration by the programme board in advance of recommendations going forward to wider governance.*
- *Paper in relation to the approach to charging for the primary care extraction part of the programme will be developed for the board.*

**EXISTING ACTION (46) CLOSED:**
*Board to review the CDO Briefing (Geraint paper).*
- *Review comments received. Agreed to close.*

**EXISTING ACTION (47) CLOSED:**
*Board to nominate people to support the prioritisation approach (to be led by Peter Flynn).*
- *All nominations received and Peter Flynn arranging meetings/has met with nominated individuals.*

| 10 | **AOB** |

Jeremy Thorp raised an item to explain that, in the HSCIC, an exercise previously took place to go out to customers and look at what they had done/what they were doing. He explained that the HSCIC now wanted to do this on a larger scale and that – for information – the intention was that it would include a number of people from this board.

TK also explained the Informatics Governance and Accountability Review (IGAR) which is currently taking place and that care.data is one of the programmes subject to this review. In respect of this, two board members (Chris Carrigan and Neil Stutchbury) have been nominated

to be involved (for interview by the IGAR panel).

**Next Board meeting**

**Tuesday 13th May 2014: 2.30 – 5.00**