## HSCIC Pseudonymisation Review Steering Group

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| **Date:** | **Wednesday 14 January 2015** | **Meeting Nr:** | **8** |
| **Location:** | **By Conference Call** | | |
| **Purpose:** | **Ratified at February Steering Group** | | |

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| **Attendees:** | **Role** | **Organisation** |
| Anthony Chuter | Patient Representative |  |
| Kambiz Boomla | Observer | Confidentiality Advisory Group |
| Ian Herbert | Primary Health Care IT Specialist | BCS |
| Nicholas Oughtibridge | Lead – Code of Practice for Confidentiality | HSCIC |
| John Parry | Medical Director | TechUK |
| Hashim Reza | Consultant Psychiatrist | Oxleas NHS Foundation Trust |
| Jill Reeve | Project Support Officer | HSCIC |
| Chris Roebuck (Chair) | Benefits & Utilisation Director and Review Co-ordinator | HSCIC |
| Matt Spencer | Pseudo Review Project Manager | HSCIC |
| Dave Wilby | Business Analyst | HSCIC |
| Tim Williams | Observer | Clinical Practice Research Data Link |
| **Apologies** |  |  |
| Paul Croft | Business Requirements Analyst | HSCIC |
| Paul Cundy | GP | General Practitioners Committee & BMA |
| Harvey Goldstein | Academic expert on Data Linkage | UCL & University of Bristol |
| Wally Gowing | Pseudonymisation Advisor | Observer |
| Xanthe Hannah | Observer | NHS England |
| Alan Hassey | GP | IIGOP |
| Julia Hippisley-Cox | Academic expert on Data Linkage | Nottingham University |
| David Ibbotson | Programme Head, Care.data | HSCIC |
| Phil Koczan | GP | RCGP/Health Informatics Group |
| Geraint Lewis | Chief Data Officer | NHS England |
| John Madsen | Head of Productivity & Efficiency | HSCIC |
| Dawn Monaghan | Observer | Information Commissioners’ Office |
| Richard Pantlin | Social Care Representative |  |
| John Parkinson | Observer | Clinical Practice Research Data Link |
| Daniel Ray | Head of Chief Information Officer Network | University Hospital Birmingham |
| Eve Roodhouse | Director care.data | HSCIC |
| James Wood | Head of Infrastructure Security | HSCIC |

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| **1.0** | **Welcome and Introductions** | |
| 1.1 | The Chair asked that the Review’s project manager confirms attendees for future meetings, February and March, to ensure the meetings will be quorate. | |
|  | The Chair gave an update on HSCIC by confirming the recent Code of Practice on confidential Information (CoP) has been approved by the Secretary of State, Dan Poulter, NHS England and the wider HSCIC and that it has now been published. | |
|  | A member mentioned the Code of Practice has been reviewed by the Information Commissioners Office (ICO) as part of its development. The definition of good practice for pseudonymisation was identified as requiring further development as an output of the pseudonymisation review. | |
|  | The Chair stated there is strong desire from the SofS and Dan Poulter to deliver on the CoP and that the additional practices on pseudonymisation mentioned above should be addressed. | |
|  | The Chair updated the group on progress made on Data Applications processed by the HSCIC and that the Data Release Register, showing who and for what purpose had received data from the HSCIC, has been published on the HSCIC website. This is the fourth version of the register and will be updated on a quarterly basis. | |
| **2.0** | **Review of Minutes/Actions** | |
| 2.1 | The November minutes (amended from December steering group) were reviewed. The project manager advised comments were received electronically from a member and amendments were made and approved by that member, these changes are included in the version being reviewed at today’s meeting. A page by page walkthrough confirmed the changes made and no further comments were raised by the group. The group therefore ratified the minutes and that they should be published on the Review’s website. | |
| 2.2 | The December minutes were reviewed with following comments raised. | |
|  | 2.2.1 | The Patient representative stated he was in attendance. |
|  | 2.2.2 | The Chair stated that Carl Vincent responsibilities for Information & Analytics are on an interim basis. The text in para 1.1 to be amended to reflect this. |
|  | 2.2.3 | A member commented on the statement in para 2.2.4 – Action 35, regarding Patient Objections, which was closed in December’s meeting. Had there been any development on new codes associated with patient objections and the need for sharing based on consent by 2020. The Chair suggested this topic be picked up as an AOB item in today’s meeting. |
| **Action No. 1:** | | **Project Manager to amend December minutes to reflect above comments and publish both November’s and December’s minutes on the Review’s website.** |
| 2.3 | **Review of Actions** | |
|  | 2.3.1 | **Action 35** –An update on Patient Objections, following comment raised in para 2.2.3 above, was provided by the Chair. The HSCIC Board has been carefully considering the issue. The position on GP data that uses codes for Patient Objections affects two read codes which require reviewing for impact on patient objections. This information has not been extracted from GP systems yet. |
|  | 2.3.2 | The member raising the query, in para 2.2.3, commented that GP data has a lot of read codes e.g. Diabetes dataset. National Information Board has looked at this issue. |
|  | 2.3.3 | The Chair stated the challenge is to come up with the best possible solution in the short term and alongside this determine and make steps towards an optimum longer term solution for objection and consent management across the system. The Review should be aware of developments of this work. |
|  | 2.3.4 | **Action 23** – The project manager confirmed there had been no response received form Mark Elliot – University of Manchester for early sight of his ‘Best Practice’ book. The project manager will continue to chase up Mark Elliott. |
|  | 2.3.5 | **Action 31** – The ToR for Pseudo @ Source sub-group is still outstanding. The project manager will continue chasing the ToR and its publication on the Review’s website. |
|  | 2.3.6 | **Action 37** – A Standards & Terminology sub-group member updated the group on progress on the Pseudonymisation Context paper. A number of drafts have been in circulation amongst the S&T sub-group and comments addressed including those where agreement could not be achieved. There is still considerable concern about Pseudonymisation as a term. |
|  | 2.3.7 | Another member commented that the term is a legal term but has overlap with the Anonymisation term. If the data is able to be discovered then the data is not anonymised. The HSCIC Code of Practice has definitions for pseudonymised data and anonymised data and offered to circulate a copy of the Code to the Steering group. |
|  | 2.3.8 | The S&T sub-group member asked steering group to review the latest Pseudonymisation Context paper and provide any comments within a fixed time so changes can be made in time for February’s steering group meeting. Subsequent to the meeting the paper was circulated with a review deadline of Wednesday 21January. |
| **3.0** | **Pseudo @ Source Sub-Group Update** | |
| 3.1 | The Pseudo at Source chair could not attend today’s meeting but had provided a progress report for review by the group. The project manager provided a walkthrough of the progress report’s main points. | |
|  | 3.1.1 | The Review’s Chair commented on para 3 – regarding the meaning of ‘at source’ following on from the supplier forum. “At source” could either be interpreted as meaning physically on the premises of the source data controller, as is typically the case for secondary care, or under the control of the source data controller, but physically held elsewhere, such as in the case of primary care system suppliers. |
|  | 3.1.2 | Another member commented that control of data @ source and at what geographical location is an interesting discussion but the control is the important consideration not geography. |
|  | 3.1.3 | The Chair commented that two of the points that have been made in favour of pseudonymisation at source have been around 1) retaining local controllership of the data and 2) avoiding having large quantities of data with identifiers held at a single location. He further commented that a situation whereby a few organisations acted as data collators for the identifiable data under controllership of the data suppliers would address point 1), but not point 2). |
|  | 3.1.4 | The member who commented at 3.1.3 further commented that size and characteristics of the organisation is key to how Data Controllers impact assess the level of risk. For paper records the risk is considered to be inherently higher. |
| **4.0** | **Data Linkage & Data Quality Sub-group update** | |
| 4.1 | The Chair of the sub-group updated the steering group on activity. | |
| 4.2 | There has been a refocus of activity towards a backup plan to deliver the required reports from this sub-group. This has been necessitated by the delay and difficulties in achieving approvals for the use of HES data to support the original data linkage CPRD/HES protocol. | |
| 4.3 | An internal HSCIC team is developing a ‘theoretical paper’ to provide the logical conclusions on data linkages, data quality and different approaches to linkages. It is also looking to provide a high level view on ‘Probabilistic matching’. | |
| 4.4 | A number of work streams are being set up with internal owners assigned and timelines for delivery to be agreed. | |
| 4.5 | A sub-group member provided an update on approvals for CPRD data to be used for the CPRD/HES protocol. A position statement has been provided to the CPRD approvals board and this is currently under review in order to provide, in first week of February, a final version for presenting to CAG and or DAAG. The group discussed the current protocol paper and whether it remains fit for purpose. The Chair stated that it remains on the sub-groups work plan but needs to be reviewed in light of the proposed theoretical paper being developed. | |
| 4.6 | The chair of the Data Linkage & Data Quality sub-group in closing his update invited the group to comment on Harvey Goldstein’s ‘Privacy’ paper. The review’s project manager confirmed an updated version of the paper had been provided and this would be circulated to the group for comment. | |
| **5.0** | **Standards and Terminology sub-group update** | |
| 5.1 | The sub-group chair didn’t attend today’s meeting. It was noted the discussions which arose in above para 2.3.6 had provided the update on current activity of the sub-group. The project manager advised he would be meeting the S&T chair w/c 19 January and would circulate the Pseudonymisation context paper as well as any other updates to the group for comment. | |
| **6.0** | **Pseudonymisation Review – Work Plan** | |
| 6.1 | The Chair commented that there is still much to do and that it is likely the Review’s work will continue beyond the end of March. The current work plan has dependencies on a number of its deliverables from the Standards & Terminology sub-group and these need prioritising to achieve the timescales in the work plan. | |
| 6.2 | The Chair further commented that the Review’s Final Report needs to be coherent and use agreed terms from across the Review. | |
| **7.0** | **AOB** | |
| 7.1 | The Chair asked for comments on the merits of conducting the groups meetings by tele conference call or face to face. A range of views were expressed by members with some saying face to face is preferable so long as progress was being derived. Another member suggested voice quality was better when it was just an audio conference call as having some on a conference phone and some in a face to face meeting caused different levels of voice quality to occur. Video conferencing was also suggested as an alternative however there may be technology challenges due to the disparate locations of group members. | |
| 7.2 | The Review’s project manager confirmed February and March’s meeting were to be held at Tavistock House, London. The Chair asked the project manager to canvas views on type of meeting and to confirm as early as possible the number of confirmed attendees. | |
| **8.0** | **Next Meeting** | |
|  | Wednesday 11 February 2015 at 1100 to 1300 at Tavistock House, London. | |