## HSCIC Pseudonymisation Review Steering Group

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| **Date:** | **Thursday 21 May 2015** | **Meeting Nr:** | **12** |
| **Location:** | **Conference Call**  |
| **Purpose:** | **For Ratification at July Steering Group** |

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| **Attendees:** | **Role** | **Organisation** |
| Antony Chuter  | Patient Representative |  |
| Paul Croft | Business Requirements Analyst | HSCIC |
| Harvey Goldstein | Academic expert on Data Linkage | UCL & University of Bristol |
| Wally Gowing | Pseudonymisation Advisor | Observer |
| Ian Herbert | Primary Health Care IT Specialist | BCS |
| Nicholas Oughtibridge | Lead – Code of Practice for Confidentiality | HSCIC |
| John Parry | Medical Director | TechUK |
| Chris Roebuck (Chair) | Benefits & Utilisation Director and Review Co-ordinator | HSCIC |
| Matt Spencer | Pseudo Review Project Manager | HSCIC |
| Marc Taylor | Observer | Confidentiality Advisory Group |
| Tim Williams | Observer | Clinical Practice Research Data Link |
| James Wood | Head of Infrastructure Security | HSCIC |
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| **Apologies** |  |  |
| Kambiz Boomla | Observer | Confidentiality Advisory Group |
| 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 |
| Sean McPhail  |  | Public Health England |
| Dawn Monaghan | Observer | Information Commissioners’ Office |
| Daniel Ray | Head of Chief Information Officer Network | University Hospital Birmingham |
| Hashim Reza | Consultant Psychiatrist | Oxleas NHS Foundation Trust |
| Eve Roodhouse  | Director care.data | HSCIC |
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| **1.0** | **Welcome and Introductions** |
| 1.1 | The Chair welcomed everyone to Steering Group’s twelfth meeting and thanked the group for its contributions over the past weeks.  |
| **2.0** | **Review of Minutes & Actions** |
| 2.1 | **Minutes** |
|  | 2.1.1 | The draft April Steering group minutes were sent for review on 13th May with a request for any comments before May’s Steering group.  |
|  | 2.1.2 | No comments had been received so the Steering Group were asked to review today. No comments were raised so the Steering Group Chair stated April’s minutes were ratified and should be published on the Review’s website.  |
| 2.2 | **Action Log Review** |
|  | 2.2.1 | Action 23 Mark Elliott paper – Draft version expected in next week. Once received to be circulated. |
|  | 2.2.2 | Action 521 – Review’s PM to investigate contacts with patient representative groups – Ongoing. |
|  | 2.2.3 | Action 53 – Draft Section 5 of Steering Group ToR to be re-issued as an appendix for review at next meeting. |
|  | 2.2.4 | Action 56 – Remains ongoing subject to revisions underway for DLDQ04 |
|  | 2.2.5 | Following actions were agreed as closed:* 47 – S&T Chair to complete Standards paper approvals outside of steering group.
* 48 – Confirm if removal of sensitive codes identifiers in SUS is undertaken.
* 49 – Steering Group Chair to review ToR for new IGARD advisory group
* 50 – S&T to contact DAAG about Section 4.4 in Context paper.
* 52 – Review’s PM to confirm latest meeting dates schedule.
* 54 – S&T Chair to complete discussion on HSCIC Code of Practice.
* 55 – Review’s PM to add purpose statement to PS03 deliverable.
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| 3.0 | **HSCIC Update** |
|  | 3.1 | The Chair provided an update on Data Services for Commissioners (DSfC). This HSCIC programme has been set up to support Commissioning purposes. This will replace the current arrangements of Data Services Commissioners Regional Offices (DSCRO) operating from 8 locations and are seconded to HSCIC. DSCROs currently access identifiable data and then onward send pseudonymised data to Commissioning Support Unit’s (CSU) and Clinical Commissioning Groups (CCG).This arrangement will end at some point and to ensure continuity of service, to commissioners, a new platform is being put in place to manage data to commissioners. |
|  | 3.2 | A Steering group member asked whether the new service will undertake data linkage. The Chair confirmed that the service would undertake data linkages. |
|  | 3.3 | Another Steering group member asked if CCGs will have access to the data. A member of the HSCIC at the meeting stated that details are not yet finalised but currently it is expected that Commissioners would have access to pseudo data and then link these to local data flows via CSUs. |
|  | 3.4 | The Steering group member who asked the question at 3.2 asked how will the Review inform the proposed the DSfC platform. The Chair stated the Review will inform on the Pseudo activities expected to be included in the new platform.The Steering group member further raised a concern that pseudo data not being anonymised there is still a risk of identifying patient data and asked if the new service is for clinical data.The HSCIC member, who provided a response to 3.3, confirmed the new service is not for clinical data. Commissioners always want access to identifiable data but are not involved in direct care. Risk Stratification is an example where there are challenges for direct care and what commissioners can see.The above Steering group member whether the Review is influencing the direction of travel and can any questions from the Steering group be presented to DSfC.Another Steering group member stated there is a need to ensure DSfC are clear on how pseudonymisation is used.Another Steering group member that he was aware of the work undertaken by Helen Brown at NHSE in terms of improving data quality. However for Commissioning Data Sets (CDS) there is a need to be clear on how pseudonymisation is used.The Chair in closing the above discussion confirmed the Review’s output will be used to inform HSCIC programmes, including DSfC, should consider the use of pseudonymisation in its planning. |
| 4.0 | **Data Linkage & Data Quality Update** |
|  | 4.1 | The Chair presented the sub-groups DLDQ03 – Impact of Pseudonymisation on Data for ratification by the Steering. This deliverable had completed its sub-group review and been formally approved.No comments were recived form the Steering group therefoee the Chair requested this be ratified and added to the Review’s deliverables for use in it’s final report. |
|  | 4.2 | The data linkage paper DLDQ04 has undergone a number of sub-group reviews. Following a review of comments received, a new version will be issued fby the internal HSCIC team for review by the sub-group.  |
| 5.0 | **Terms of Reference** |
|  | 5.1 | The Chair outlined the reasons behind proposed rewriting of the ToR which had been sent to members prior to the Steering group meeting. The reasons are there had been diverse debate on how the Review achieves consensus and there needs to be clarity on how review’s, of deliverables and final report, are undertaken. |
|  | 5.2 | A Steering group member stated that there is a need to resolve the concern raised by another member on changing the ToR so late in the Review’s work. And that the proposed changes were a good attempt at trying to answer how consensus and reviews are to be achieved.However in the last paragraph of the draft ToR is not clear how No Consensus is involved. The paragraph needs to be made clearer on how this is managed. In addition the process for ratification of the final report, doesn’t seem to resolve the concerns expressed at the last Steering group meeting. |
|  | 5.3 | Another Steering group member stated the example of Standards & Terminology deliverables were affected by issue of achieving consensus. |
|  | 5.4 | Another Steering group member stated the last but one paragraph needs to be extended to cover sub-group deliverables not just the final report.  |
|  | 5.5 | The Chair in closing stated the draft ToR, section 5, is to be rewritten and added as an appendix to the current ToR for review at the met Steering group. |
| **6.0** | **Standards & Terminology Sub-Group Update** |
| 6.1 | The Standards & Terminology Chair provided a general update on the sub-groups work. |
|  | 61.1 | The sub-groups Context paper has been updated following comments received as had the Legislation paper. |
|  | 6.1.2 | The update from the S&T Chair was stopped to allow the Chair of Pseudo@ Source sub-group, joining the meeting by conference call and had another meeting to attend, needed to provide the P@S update at this point in the meeting. |
| 7.0 | **Pseudo @ Source sub-group update** |
| 7.1 | The Chair of the sub-group provided an update on the groups work.A call in the previous week was held and two deliverables were reviewed and approved for submission to Steering group.A further sub-group call will be held in June to review the remaining deliverables.  |
|  | 7.1.1 | The sub-group Chair stated the group will provide the evidential material to support the Review’s work. In stating this sub-group Chair asked the Steering group if this is the agreed process. |
|  | 7.1.2 | A Steering group member commented that specific recommendations should not be presented but the evidence should be relevant and appropriate to readers. |
|  | 7.1.3 | Another Steering group member stated he was not comfortable with the previous statement as he thinks sub-groups should be able to provide the ‘recommendations’ to Steering group. |
|  | 7.1.4 | The Sub-group Chair agreed, with the comment at 6.1.3, and suggested that a statement that Subject Matter Experts (SME) input has provided the evidence.  |
|  | 7.1.5  | Another Steering group member suggested there was danger in this approach, in providing a Statement, but that it help guide opinions.  |
|  | 7.1.6 | Another Steering group member suggested some conclusions drawn from the Sub-groups would be useful.  |
|  | 7.1.7 | Another Steering group member suggested a purpose, in the Review’s products, should be put forward. The sub-group Chair agreed that context of purpose would help draw out conclusions.  |
|  | 7.1.8 | The Steering group Chair commented that it is right to focus on evidence for example Impact on Security. A comment from a HSCIC member said some areas are not black and white for example Pseudonymised identifiers resulting in different lengths.The Steering group Chair stated the deliverables should be based on assumptions. |
|  | 7.1.9 | The Sub-group Chair presented the PS03 deliverables for ratification. This deliverable has previously been presented for information but now presented for ratification. As no comments were raised the Steering group Chair confirmed PS03 was ratified. |
|  | 7.1.10 | An update was provided by a HSCIC member on ***PS07 - Report on implications of P@S on HSCIC DSA, Patient Consent and transparency reqs.***This deliverable has been through sub-group review and comments raised have been addressed. The deliverable needs to be presented to HSCIC Information Governance leads to confirm the impacts listed, relating to SARS and S10, are correct.  |
| 7.2 | A Steering Group member from CAG, joining the meeting by conference call at 11.20, asked if there was a definition for Anonymisation. It was confirmed by the Steering group member from S&T sub-group that there was and it’s in the Review’s glossary. The Steering group member in asking the question further asked if this was an authorative definition and not just the author’s view.The S&T sub-group member stated that the definition is between two points, Anonymised enough and Anonymised too much, the sub-group had to agree the key definition that could be used in the Review’s work.The CAG member commented that the term ‘effectively anonymised’ is the concern for him.The S&T member stated the sub-group didn’t use that term as it focused on de-identification. |
|  | 7.2.1 | Another Steering group member stated the reality is that there is no clarity on the term used. Confusion on the term in use can depend on ‘dataset view’. The glossary focusses on the ‘individual record’ needs to be made clearer so confusion is reduced.The S&T member agreed and stated producing the glossary is important. |
| 7.3 | The P@S Chair left the meeting at this point so the Steering group Chair asked the Chair of S&T sub-group to continue his update. |
| **8.0** | **Standards & Terminology Sub-Group Update (continued from 6.1.2)** |
|  | 8.1 | The CAG member continued his comments definition for ‘Anonymisation’ – CAG will in the future have to advise HSCIC on the release of data so the question is important. Therefore the context of the sub-groups Glossary needs to nail the definition on pseudonymisation so data is released with ‘no risk’.  |
|  | 8.2 | Another Steering group member suggested this could be labelled in Disclosure Risk definition. And perhaps the definition should be further elaborated to satisfy the question raised by the CAG member. |
|  | 8.3 | The CAG member agreed this approach could be accepted so long as ‘Risk Management’ as a process is clearly documented. |
|  | 8.4 | The Steering group Chair commented that the work of the IGA, on Anonymisation Standard, should be looked at to see if the questions raised could be addressed through their work. |
|  | 8.5 | The CAG member further stated the reason for raising the question, in 5.1, is that the level of risk management needs to be made clearer. It would be helpful if we have something more precise to inform CAG. |
|  | 8.6 | Another Steering group member raised a reservation on the previous request in that the context of access to data is important to be aware of when looking at the definition. For example the DPA forces you to consider if the data is identifiable. |
|  | 8.7 | The CAG member stated the group should say ‘as much as is appropriate’ and whether a standard should be followed. So the HSCIC can be clear on saying that you can release data based on a legal/agreed point.  |
|  | 8.8  | The Steering group Chair commented that a scientific approach on looking at sharing of data, with general principles on types of data that can be shared, should be based on levels of risk. Suggested the IGA should lead on this as the need for a scientific approach is needed. |
|  | 8.9 | The S&T Chair proposed adding a statement to cover off the sharing, risk and release of data to the glossary paper and to include a reference to CAG work on the definition. |
|  | 8.10 | The CAG member stated that CAG is not producing definitions. The S&T Chair offered to add statement that CAG are aware of the sub-groups work. |
|  | 8.11 | The CAG member commented that the terms in Context paper (v27) should have a definition in the glossary.  |
| 8.2 | The S&T Chair provided an update on the Context for Pseudonymisation paper (v27). The red text in version presented to Steering group resulted from comments made by a Steering group member.The following sections have been amended:Section 1.1 – Particular point on Data Services for Commissioners made earlier in the meeting reinforces the comments received about the need for good data quality.Section 1.3 – 2nd Part – To avoid the functional anonymisation defined by the Review as De-Identification as opposed to ‘pseudonymisation’. The section to be made clearer the use of pseudonymisation term based on the glossary.Section 4.2 – Use of the terms to be clarified from the table, in Context, to Glossary. And clarify the term ‘de-identified data’. |
|  | 8.2.1 | A Steering group member stated the changes were accepted; however the HSCIC cannot publish identifiable data unless it has explicit consent from the organisation providing the data.The Steering group Chair asked if the member was commenting about publishing or disclosure data.Another Steering group member stated he would be concerned if this was about publishing.The Steering group member who made the comment about HSCIC above confirmed he was talking about disclosure. |
|  | 8.2.2 | A Steering group member stated that Section 4.1, of Context paper, needs to add ‘further controls e.g. S251’ to the section.The S&T Chair stated he wanted to state what the HSCIC is currently able to do.A HSCIC member stated second para in 4.1 covers the point made by the Steering group member.The S&T Chair agreed this was the case. |
|  | 8.2.3 | The Steering group Chair asked if the previous discussion is about what is being said about Context paper. It should be either leave as is or add a statement about legal basis?The HSCIC member asked if the first paragraph is about patient data and the second paragraph is about dissemination of data. Is the latter about patient data? |
|  | 8.2.4 | The Steering group member, who commented at 5.2.2, clarified the position by saying HSCIC can disseminate patient data based on legal basis.However the Steering group member, representing HSCIC Code of Confidentiality, stated that the paragraph under discussion cannot say ‘patient’. After discussion by several members it was agreed by Steering group that ‘Patient’ should be reconsidered. The HSCIC member offered to work offline with the S&T Chair to come up with a replacement sentence particularly as there is danger in changing the wording of the HSC Act in the paper. |
|  | 8.2.5 | The CAG member commented that the previous discussion is also linked to issue he raised on Legislation paper and that it should describe the legal differences more clearly. |
|  | 8.2.6 | The Steering group Chair stated the section with proposed changes be circulated to steering group for final comments. The Chair offered a comment that the De-Identification definition in Context paper is not consistent with the Glossary. The Chair stated he was happy with how the term was used in the Context paper so amend the term in the glossary. |
|  | 8.2.7 | The Steering group Chair in closing the discussion stated the Context paper is ratified subject to the changes specified earlier are made and that not to reopen debate on the paper again unless substantive material changes were proposed.  |
| 8.3 | The Standards & Terminology Chair presented the Legislation paper |
|  | 8.3.1 | The Legislation paper had been reviewed at the last Steering group for information. Since then the paper has had a section on the Human Rights Act added and asked that the paper now be reviewed and ratified. |
|  | 8.3.1 | The CAG member commented that he was not sure what the purpose of the Legislation paper was. It seems to start off with current legislation then moves onto other areas for legislation. The paper should reference the same terms used in the sub-groups Context/Glossary papers. The CAG member further commented that the HSC Act brought changes in relationships. The Care Act / Schedule 7 / para 8 sets out matters for HSCIC and CAG whilst Sections 117 & 110 of the Care Act sets out functions of the HRA and between them set out the relationship between the HSCIC and the HRA.The CAG member further commented that an appendix should be added to the Legislation paper to reference the glossary. |
| **Action No. 1:** | The Standards & Terminology sub-group Chair to amend the Legislation paper and cross-check with the CAG member. |
| **9.0** | **AOB** A Steering group member commented that a face to face meeting for the next Steering group is preferred. The Steering group Chair agreed and asked the Review’s project manager to arrange this and to ensure deliverables still to be reviewed are made available for the next meeting.A HSCIC representative commented that sub-group testing of headlines from the deliverables needs to be undertaken. This was agreed by all and the Review’s project manager should look to prioritise this as soon as possible. |
| **10.0** | **Next Meeting – To be confirmed** |