## HSCIC Pseudonymisation Review Steering Group

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| **Date:** | **Friday 24 April 2015** | **Meeting Nr:** | **11** |
| **Location:** | **Conference Call**  |
| **Purpose:** | **For Ratification at May 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 |
| Sean McPhail  |  | Public Health England |
| Nicholas Oughtibridge | Lead – Code of Practice for Confidentiality | HSCIC |
| Chris Roebuck (Chair) | Benefits & Utilisation Director and Review Co-ordinator | HSCIC |
| Matt Spencer | Pseudo Review Project Manager | HSCIC |
| Tim Williams | Observer | Clinical Practice Research Data Link |
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| **Apologies** |  |  |
| Kambiz Boomla | Observer | Confidentiality Advisory Group |
| Harvey Goldstein | Academic expert on Data Linkage | UCL & University of Bristol |
| 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 |
| Dawn Monaghan | Observer | Information Commissioners’ Office |
| John Parry | Medical Director | TechUK |
| 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 |
| Dave Wilby  | Business Analyst | HSCIC |
| James Wood | Head of Infrastructure Security | HSCIC |
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| **1.0** | **Welcome and Introductions** |
| 1.1 | The Chair welcomed everyone to Steering Group’s eleventh meeting and thanked the group for its contributions over the past weeks. The attendees were confirmed as making the meeting quorate however two members could not join the start of meeting so an amended agenda was adopted to allow the meeting to start.  |
| **2.0** | **Review of Minutes & Actions** |
| 2.1 | Minutes |
|  | 2.1.1 | The draft minutes for March Steering group minutes were remotely reviewed prior to today’s meeting. A number of comments had been received and included in an amended draft submitted to Steering group on 23 April. This was reviewed in today’s meeting. |
|  | 2.1.2 | A Steering group member commented on paragraph 2.2.4 – the original minutes didn’t reflect what was said in the previous meeting. The member had provided by email a proposed amended text which was accepted by the group.  |
|  |  | No other comments were raised and Steering group Chair stated the minutes were approved subject to the amended para 2.2.4 text being added.  |
| 2.2 | Action Log Review |
|  | 2.2.1 | Action 23 – Remains open. The Review’s project manager is in contact with Mark Elliott and understands a draft publication of Mark’s Best Practice book is due 15 May. |
|  | 2.2.2 | Action 48 – The Steering group Chair provided the response to the investigation on whether sensitive codes are removed automatically from SUS. A Data Set Change Note (DSCN 4198/99) confirms sensitive codes are removed from identifiers. |
|  |  | A Steering group member stated that Sexually Transmitted Diseases (STD) is now known as Sexually Transmitted Infections (STI). |
|  |  | An HSCIC attendee stated the DSCN refers specifically to SUS. The HSCIC website has definitions for Care.data and GP Extracts. |
|  |  | The Steering group Chair clarified the definitions available on HSCIC website relates only to Care.data and that Mental health is not included. |
|  |  | The DSCN has been made available to Steering group therefore the action is closed. |
|  | 2.2.3 | Action 49 – Terms of Reference on new HSCIC advisory group.  |
|  |  | The Steering group Chair provided a verbal update to the group.  |
|  |  | Consultation on the new advisory group was due to start. On the specific question of whether there would be a Patient Representative on the new group the answer is no. There would be lay members on the group who will cover Patient views.  |
|  |  | A Steering group member asked if the consultation covers the IAG. The Chair responded that is does not.  |
|  |  | The Steering group member raised concern about the lack of consideration for patient representation and stated this was indicative of how the HSCIC had got previous advisory groups wrong. |
|  |  | The Chair asked that the Steering group member email his concerns direct to the Chair of the Data Access Advisory Group (DAAG) who is undertaking the consultation.  |
|  | 2.2.4 | Action 50 – Standards & Terminology Chair to contact DAAG about section 4.4 in sub-group’s Context paper. |
|  |  | The S&T Chair confirmed he had contacted the DAAG Chair and had also received very useful information from Confidentiality Group (CAG) regarding the application of law in regards to Data being sent outside of the European Union. |
|  |  | Following the information, received from DAAG and CAG, section 4.4 has been modified and is being presented to today’s Steering group for ratification.  |
|  |  | The action was therefore agreed as closed. |
|  | 2.2.5 | Action 51 – Review’s project manager to investigate contacts with patient groups that are available through HSCIC comms. |
|  |  | The Review’s project manager updated the group that he had contacted HSCIC comms but that no details had yet been provided. This action relates to the potential need to contact patient groups about the Review’s final report and as such the project manager will continue to look into whether any contact lists are available.  |
| **3.0** | **Standards & Terminology Sub-Group Update** |
| 3.1 | The Standards & Terminology Chair provided a general update on the sub-groups work. |
|  | 3.1.1 | There has been a lot of engagement and input to the sub-groups deliverables. The Context deliverable is now at version 26; the Standards paper is at version 14. |
|  |  | The Vocabulary paper is still undergoing revision following requests for definitions of pseudo at source and other items at March’s Steering group. This paper will be presented for ratification at May’s Steering group. |
|  |  | There has been a change in the sub-groups membership. Stacey Egerton has replaced Dawn Monaghan from the Information Commissioners Office. Stacey has already provided her comments on the sub-groups deliverables particularly the Standards paper. |
|  |  | The group is making progress and is presenting 3 of its 4 deliverables to today’s Steering group. |
| 3.2 | The Standards & Terminology Chair presented the sub-groups Context paper for ratification. |
|  | 3.2.1 | A Steering group member asked for clarification on what Ratification meant when reviewing papers presented to the Steering group. |
|  |  | The Steering group Chair clarified the process by stating that papers developed by sub-groups were approved by those sub-groups and that such approval, of deliverables, was then ratified by Steering group. |
|  |  | The S&T sub-group Chair provided an explanation of this process by illustrating how the Context paper was developed. This paper has been reviewed and commented many times by both the S&T sub-group as well as versions provided to previous Steering groups for review and comment. Where there were different views and disagreements then these were managed through the different versions of the Context paper. |
|  |  | The Steering group member who raised the question on ratification further stated that he didn’t understand how ratification could achieve consensus if that was the objective of the process. |
|  |  | Another Steering group member gave an opinion that consensus would be nice to achieve but that agreement on the deliverables objectives was the more likely outcome.  |
|  |  | Another Steering group member stated that a difference of opinion on the Review’s work was inevitable. The S&T sub-group Chair agreed and stated that understanding of the different viewpoints was important.  |
|  |  | The Steering group member, who raised the question on ratification, gave an illustration of his concern by saying the starting point of Pseudo @ Source sub-groups work was something he couldn’t agree to.  |
|  |  | A Steering group member stated there were different models of agreeing documents and not everyone is likely to reach a consensus view whichever model was used. However he understood the steering group member’s concern, about achieving agreement, and that the S&T sub-groups Vocabulary deliverable does provide the basis for much of the Steering groups work and as this wasn’t yet available this perhaps is causing some of the concern. |
|  |  | The Steering group Chair agreed with the last point and asked that the member with concerns, on the approval and ratification process, to raise any direct comments on the Context paper to the S&T Chair. The S&T Chair was asked to continue with presenting the Context paper.  |
|  | 3.2.2 | The S&T Chair presented the Context paper which at version 26 had undergone several reviews with many comments being raised that have been addressed. |
|  |  | The paper was last presented to March’s Steering group for Ratification. The Steering group provided the ratification with the caveat that section 4.4, about data outside of the EU, is looked at again as it implies the HSCIC is directing this. This section has been modified following confirmation from DAAG and CAG about the issue of legal position on data leaving the EU. The paper is therefore presented to the Steering group to ratify again with the modified section 4.4. |
|  |  | In presenting the paper the S&T Chair reminded the group on how the paper came about, this was following comments made by John Parkinson to the August 2014 Steering group about the need to know the where and when Pseudonymisation takes place. This includes the wider issue of de-identification processes. |
|  |  | The S&T paper in looking at the processing of identifiable data considers all of the issues raised in August 2014. It covers the HSCIC only as this is the only organisation that has a legal basis to use identifiable data for secondary use. |
|  | 3.2.3 | A Steering group member asked whether the paper considers payload data. The S&T Chair confirmed the paper does consider such data as well as other data items and whether they should be pseudonymised or not.  |
|  | 3.2.4 | Another Steering member responded by saying whilst he doesn’t necessarily agree with all the terms used in the Context paper they do form the basis to undertake the Review’s work.  |
|  | 3.2.5 | Another Steering group member stated the paper needs to include the legal framework on using data. |
|  | 3.2.6 | Another Steering group member asked if Anonymisation is covered and what this means for pseudonymisation. Another Steering group member stated that it should be made clear that Pseudonymisation enables encryption and this leads to the protection of patient identifiable data. |
|  | 3.2.7 | The S&T Chair stated the point of the Context paper is to establish the legal basis to process data and to advise on the process to pseudonymise data. If the Data Controller is assured that the organisational, technical and legal measures are undertaken and the identifiers are removed then the data can become effectively anonymised. |
|  | 3.2.9 | The S&T Chair further stated the remit of the sub group is to consider how pseudonymisation can protect patient data. This has led the sub group to look at de-identification as way of protecting patient data, as pseudonymisation is considered to be one way of protecting data and that there are other considerations to ensure patient data is protected and this is reflected in the paper. |
|  | 3.2.10 | A Steering group member in asking about anonymisation, as detailed in the Context paper, queried what the basis of the Pseudo at Source sub-groups work was. |
|  |  | The Steering group Chair stated P@S sub group is looking at the specifics of pseudonymisation at source whereas S&T sub group is looking at pseudonymisation in general terms. The fact that the Context paper is generating a lot of debate illustrates that it is a big subject. |
|  | 3.2.11 | A Steering group member stated he disagreed with the second sentence in first full paragraph of section 1.1 on page 2. |
|  |  | Another Steering group member responded by saying he understood what the previous member was saying, but the sentence referred to is looking at the legal position and not the linkage process. |
|  |  | The Steering group Chair agreed with the last comment and stated the Data Linkage and Data Quality sub group is looking at linkage issues specifically. |
|  | 3.2.12 | The Steering group member, raising the comment on the paper in 3.2.13, further stated there were large sections of the paper he couldn’t agree to and asked how agreement on such papers could be achieved. |
|  |  | Another Steering group member in commenting said he understood why the member was making the points made but thought the Vocabulary paper will answer many of the points raised. |
|  |  | The Steering group Chair confirmed sub groups are tasked with developing specific deliverables to provide the evidence base for the Review. And that they are then to be used to contribute to the Review’s Final Report. |
|  |  | In closing the review of the Context paper the Steering group Chair said the paper should be ratified subject to final comments from the member raising disagreement on the paper’s remit being responded to. |
|  |  | It was noted by another Steering group member that it would be useful to provide for the different views and that the Review should look to achieve consensus as much as possible. |
|  | 3.2.13 | Another Steering group member offered an observation on achieving consensus from other work. This was that agreement requires all to agree to something, whereas consensus does not mean agreeing to every single item, but can be summed up as ‘all members can live with the outcome’. |
|  |  | The Steering group Chair referenced Section 3 of the Review’s terms of Reference where it states ‘*Wherever possible, the steering group should reach a consensus decision for each recommendation*’. |
|  |  | The Steering group Chair in accepting that the member in making late comments on the Context paper, who was not around for several months of the Review’s operation, did feel the question on reviews and approvals should be looked at again. |
|  |  | The Chair asked the Review’s project manager to take an action to draft a new process on iterations of papers, of other members late commenting on papers and on review periods to be made clearer. |
| **Action No. 1:** | The Review’s project manager to draft a new paragraph in section 4 of the Review’s ToR for a new process to manage iterations of papers, of other members late commenting and on review periods to be made clearer. |
| 3.3 | The Standards & Terminology Chair presented the Standards paper |
|  | 3.3.1 | The Standards paper v14 was presented for Ratification. The S&T Chair mentioned section 6 as being relevant to the previous discussion on Context and that this would address many of the points made by the particular member. |
|  |  | Sections 1 – 5 have hardly changed from previous version.  |
|  |  | The Steering group Chair suggested that the member raising concerns with the Context paper, in respect of anonymisation and data linkage, provides a sentence on data linkage for the S&T Chair to consider.  |
|  | 3.3.2 | A Steering group member commented that the HSCIC Code of Practice should be included in the Standards paper and that the Code of Practice needs to have a higher status within the paper as the CoP provides the guidance to HSCIC staff on how to use pseudonymisation.  |
|  | 3.3.3  | The S&T Chair asked the Steering group on what should go into the HSCIC Code of Practice to in order to respond to the Steering group member’s request. |
|  | 3.3.3  | The group agreed that the S&T Chair should take the issue off line with the member covering HSCIC CoP and report back to the group. |
|  | 3.3.4 | Another Steering group member asked whether ISO25237 was included in the Standards paper. The S&T Chair confirmed the Standards paper does reference the ISO25237.  |
| **Action No. 2:** | Standards & Terminology sub-group Chair to meet with the Steering group member about recommendations for pseudonymisation to be included in the HSCIC Code of Practice and report back to the group. |
| 3.4 | The Standards & Terminology sub-group Chair presented the Legislation paper. |
|  | 3.4.1 | The Pseudonymisation Legislation Reference List (v14) was presented for information to the steering group. |
|  | 3.4.2 | The Steering group commented that in general the paper as presented is a good paper.  |
|  |  | A Steering group member asked how the paper relates to Pseudonymisation @ Source and suggested and Introduction needs to be add to clarify the purpose of the paper. |
|  |  | The S&T Chair agreed that the Introduction and Purpose section should be modified and that reference should be included to the Human Rights Act. |
| **4.0** | **Pseudo @ Source sub-group update** |
| 4.1 | The Chair of the sub-group did not attend the Steering group due to competing priorities. The Progress Report was presented to the Steering group by the Review’s project manager. |
| 4.1 | Progress on deliverables in the last month had continued to be impacted by delays in review and approvals for several of the sub group’s deliverables. These are expected to continue into early May when new draft versions will be made available for sub group review. |
| 4.1 | The Review’s project manager outlined the current status on the following deliverables. |
|  | 4.1.1 | **PS03 - Pseudonymisation Products & Suppliers** |
|  |  | This deliverable is presented to today’s steering group for ratification with comments raised that it should include lists of other suppliers of pseudonymisation functionality for example GP system suppliers as well as bespoke suppliers using common ETL tools such as Oracle, SQL server and SAS.  |
|  |  | However, such product listing was deemed to be out of scope for the purposes of the sub group’s work. |
|  |  | The Steering group were therefore asked to ratify the paper as presented today. |
|  |  | It was commented that the paper needs to provide a statement on the purpose of the paper. |
|  |  | The Steering group Chair agreed this is needed and with no other comments being raised stated the paper is ratified subject to the purpose statement being added. The Review’s project manager was asked to undertake this and to circulate a final version to the steering group. |
| **Action No. 3:** | Review’s project manager to add a purpose statement to PS03 deliverable and circulate to the Steering group as a ratified paper. |
|  | 4.1.2 | **PS04 – Pseudonymisation Market Assessment** |
|  |  | This deliverable is in two parts, a questionnaire to suppliers (listed in PS03) and an assessment of supplier responses. |
|  |  | Both parts of PS04 have been presented to the Steering group and a number of comments were raised. These were to add a definition for pseudonymisation at source and the addition of further questions to the questionnaire. |
|  |  | There were no comments raised about the assessment criteria when previously presented. |
|  |  | The internal team in considering the suggested changes to the Questionnaire have not included the *pseudonymisation at source* definition as the product is looking at pseudonymisation products in the market and it should not constrict supplier responses by including the definition. In respect of the further questions, on scalability amongst others, the internal team have been advised by HSCIC Procurement not to add any further questions. This is due to HSCIC Procurement policy on communicating with open market suppliers. The internal team is therefore unable to resend the questionnaire with any further questions. |
|  |  | Both parts of PS04 therefore remain unchanged and the internal team is progressing with obtaining supplier responses in order to complete the Market Assessment. Once the assessment is completed PS04 deliverable will be presented to the Pseudo @ Source for review and approval before being presented to the Steering group. |
|  | 4.1.3 | **PS05 – Impact of Pseudonymisation on different** **models** |
|  |  | This deliverable was presented to March’s Steering group *for information only. A*n action was raised that the sub group look at procuring a qualitative researcher to look at the 272 comments PS05 which were obtained through various stakeholder events. |
|  |  | Due to HSCIC procurement rules and timescales to procure such resource being outside of the Review’s timeline, an internal qualitative researcher has been asked to look at the data. An outline approach to the research is being drafted and will be shared with the sub-group for comment. The researcher was provided with relevant PS05 material only, no other sub-group deliverables have been made available, to ensure as impartial a review of the data as possible. It is expected that the results of the research and a summary will be made available to the sub-group w/c 11 May. |
|  | 4.1.4 | **PS06 – Impact of pseudonymisation on Interoperability standards** |
|  |  | This deliverable has undergone one round of sub-group review and is currently being further developed following internal subject matter expert review. A new draft is to be issued for sub-group review by 29 April.  |
|  | 4.1.5 | **PS07 – Implications of Pseudo @ Source on information Governance and Transparency** |
|  |  | This deliverable has undergone one round of sub-group review followed by discussions between the author and HSCIC subject matter experts. A new version, 0.4, has been created and comment review sheet updated with internal team responses. The new version is due to be sent out week commencing 27 April for comment with a 5 day review period deadline. |
|  | 4.1.6 | **PS11 - Relative security benefits and risks of different pseudo models** |
|  |  | This deliverable is still undergoing internal team development. A draft version will be issued to the sub-group by Friday 24 April. |
|  | 4.1.7 | **PS13 - Summary on other organisations ability to pseudonymise data** |
|  |  | This deliverable is still undergoing consideration with respect to required inputs to complete. In addition to considering the outputs of the sub-groups other deliverables it is also expecting to cover other systems and services use of pseudonymisation and other sectors, such as Social Care, use of pseudonymisation.  |
| 5.0 | **Data Linkage & Data Quality sub-group update** |
| 5.1 | The sub-group Chair presented the DLDQ03 paper for ratification |
|  | 5.1.1 | This paper has undergone several sub-group reviews and has been approved by the sub group. The paper is therefore presented now for Steering group ratification. |
|  | 5.1.2 | A HSCIC attendee commented that an introduction section setting out the purpose of the paper should be added. This was agreed by steering group members. |
|  |  | The Chair of the DL & DQ sub group asked the Review’s project manager to ensure an introduction is added to the paper. |
|  | 5.1.3 | A Steering group member asked whether the paper provides any measuring of NHS Number matching but is not the same person.  |
|  |  | The sub group Chair stated that measurement of such instances is not being undertaken but commented that the sub groups other paper, DLDQ04 Data linkage, may have some content around this. |
|  |  | The Chair asked the Review’s project manager to either check if DLDQ03 includes any such measurements, accuracy of the NHS Number, and to reference the content to the Audit Committee Report and the sub groups other paper if covered there.  |
|  | 5.1.4 | No other comments were raised and the sub-group Chair said the paper should be updated with the introduction section and reference to any measurement of NHS Non matching undertaken. Subject to these two actions the paper is ratified. |
| 5.2 | The sub-group Chair updated the group on DLDQ04 Data Linkage paper. |
|  | 5.2.1 | This paper has undergone several reviews and revisions. It is currently undergoing further development before being issued as a new version for sub group review in the next few days.  |
|  | 5.2.2 | A HSCIC attendee raised a question of whether there were any differences in linkage accuracy between using identifiable/identified data as opposed to pseudonymised data. |
| **Action No. 4:** | Review’s project manager to arrange for an introduction section setting out the purpose in DLDQ03 paper. And to check for and reference any content covering measurement of NHS No matching, but not to the same person, in the sub groups papers and to link the content to the Audit Committee Report. |
| **6.0** | **Review of Work Plan**  |
| 6.1 | The Reviews project manager presented a cut down version of the work plan spreadsheet showing deliverables, version number and approval and or ratification status at sub group and steering group levels.  |
|  | The project manager commented that a number of deliverables are expected to be presented to May’s Steering.  |
|  | The Steering group Chair commented that the work plan looked ambitious for May and that there is a need to look at the ratification process as well as need for review timelines to be adequate for both sub group and steering group purposes.  |
|  | The earlier discussion on achieving consensus in the groups work was raised again. Comments were made that agreement on how to represent the different views in the papers was needed. |
|  | A Steering group member offered to provide examples of how different views in documents had been represented. This offer was accepted and the member offering the examples is to send them to the Reviews project manager to consider alongside the earlier action to look at section 4 of the groups ToR.  |
| **7.0** | **Next Stage Report**  |
| 7.1 | The Review’s project manager provided a verbal update on the development of the Reviews final report.  |
|  | A high level document structure has been defined and relevant deliverables are being collated to develop the content. The project manager also advised that costs, for the different pseudonymisation models, are now to be added to the final report. These costs will involve high level estimations and will be based on assumptions that the reviews Chair and the P@S Sub group Chair have approved. |
|  | A draft version showing structure, content and costs assumptions will be presented to May’s Steering group.  |
| **8.0** | **AOB –** No items of other business were raised. |
| **9.0** | **Next Meeting –** Tavistock House, London and conference call 21 May 2015. |