HSCIC Pseudonymisation Review Steering Group

Date:	**Tuesday 17 March 2015**	**Meeting Nr:** **10**
Location:	**Tavistock House, London & Conference Call**	
Purpose:	**For Ratification at April Steering Group**	

Attendees:	Role	Organisation
Antony Chuter	Patient Representative	
Wally Gowing	Pseudonymisation Advisor	Observer
Ian Herbert	Primary Health Care IT Specialist	BCS
Julia Hippisley-Cox (dial in)	Academic expert on Data Linkage	Nottingham University
Sean McPhail (dial in)		Public Health England
Chris Roebuck (Chair)	Benefits & Utilisation Director and Review Co-ordinator	HSCIC
Matt Spencer	Pseudo Review Project Manager	HSCIC
Dave Wilby (dial in)	Business Analyst	HSCIC
Tim Williams	Observer	Clinical Practice Research Data Link
James Wood	Head of Infrastructure Security	HSCIC
Apologies		
Kambiz Boomla	Observer	Confidentiality Advisory Group
Paul Croft	Business Requirements Analyst	HSCIC
Paul Cundy	GP	General Practitioners Committee & BMA
Harvey Goldstein	Academic expert on Data Linkage	UCL & University of Bristol
Xanthe Hannah	Observer	NHS England
Alan Hassey	GP	IIGOP
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
Nicholas Oughtibridge	Lead – Code of Practice for Confidentiality	HSCIC
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
James Wood	Head of Infrastructure Security	HSCIC

1.0   Welcome and Introductions

1.1   The Chair welcomed everyone to Steering Group's tenth 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   Standards & Terminology Sub-Group Update

2.1   The Standards & Terminology Chair was asked to present Pseudonymisation Standards paper.

2.1.1   The Pseudo Standards version 12b was presented. This paper has undergone a large number of revision and comments to get to this point. A précis of the paper's main points are:

Section 2 – Six standards listed and two codes of practices.

Section 3 – Related Pseudo Standards concepts e.g. IS025237.

Section 4.2 – Data items to be pseudonymised. The paper has addressed the question of Systems that would use pseudonymisation, question on what data items need to be pseudoed and the impact of using good practice.

Overall there is a need for implementation of sections 4.1 and 4.2 to be considered.

In addition there may be a need to review the paper if Dame Fiona Caldicott's position as a Legal Data Guardian is confirmed.

The sub-group chair stated the paper is with the steering group for review and so further comments are welcomed by 28th March. The intention is to present the paper for ratification at April's steering group.

2.1.2   A steering group member asked a question on who should make the assessment on whether data items should be pseudonymised.

2.1.3   Another member asked if there should be some sort of metrics of whether data is identifiable or not.

2.1.4   The sub-group Chair suggested that the above questions should be part of the development of the De-Identification Standard.

2.1.5   The member asking about section 1.3.2 asked whether Organisations should also be confirmed as processors of data on behalf of Data Controllers; the sub-group Chair responded that this is the case and would modify the wording in 1.3.2.

2.1.6   The Review's Chair agrees that there is an art to how all of the above questions should be looked at. Dane Fiona's list and other lists are much more prescriptive on data fields and the Review should consider what is now required going forward.

2.1.7   Another member said there are concerns on the above topics in other bodies e.g. GPES IAG. The sub-group Chair thought that indicating the need for metrics, as outlined in para 2.1.3 above, would be helpful and would incorporate it into the Standards paper.

2.1.8   The Review's Chair said there are two aspects to this discussion. First is a broad set of rules needs to be in place and then specific items to be considered for pseudonymisation should be looked at by a legal body.

2.1.9   Another member suggested case studies might help to articulate the broad spectrum of views.

2.1.10   The steering group Chair said the key success criteria in the paper are whether it covers all standards and the paper as presented does. The sub-group Chair was asked to finish the paper with addition of a conclusion on implementation as discussed. The paper should then be ratified outside of the formal steering group meeting if possible.

Action No. 1:   Standards & Terminology sub-group Chair to complete Pseudo Standards paper and achieve approvals outside of steering group meeting.

2.2 The Standards & Terminology sub-group Chair presented the Context paper.

2.2.1 The Context paper (v24) was presented for ratification by the steering group.

2.2.2 The background to the paper is it was started in August 2014 in response to steering group members asking where and how pseudonymisation should be used. In the intervening time there have been a large number of revisions and a divergent set of views on the paper's direction. At March's steering group there was a comment raised that the paper should provide a definition on a number of specific terms which have now been made available in the version in front of the steering group. Since March there have been no other comments received.

2.2.3 A steering group member commenting on section 4.4, page 12, asked if it was known how many datasets are sent by the HSCIC outside of the EU.

2.2.4 Another member in stating he had not seen the paper but understood it had been reviewed by the previous CPRD member of the steering group. As part of a governance review CPRD is looking at providing appropriate controls to data access and will align with the clarity provided around the legal status of data supply outside of the EU.

2.2.5 Another member stated the Context paper was fine but felt it was missing a section on data audit trails. Is there such an audit of where data goes? Another member commented that if data leaves the EU then that's it as far as a trail goes. If data is NOT de-identified then that is a problem.

2.2.6 The member from CPRD stated that a trail of data released is maintained through CPRD contracts. These contracts can last several years and the Governance of the contracts needs to remain in step.

2.2.7 The member asking about audit trails stated the paper should also look at contract penalties. The sub-group Chair agreed that penalties are relevant, but that the detail was beyond the scope of the paper.

2.2.8 The steering group Chair said whilst there is a question on audit trails to be answered in the paper as currently there are no restrictions in place. However the HSCIC is rolling out Data Sharing Agreements (DSA) with penalties. And in addition HSCIC is exploring access to Secure Data Facilities (SDF) as a secure mechanism method and this will have audit trails of who accessed the data held in the SDF. The challenge is to achieve a balance of security with access to data.

2.2.9 A member asked whether the SDF extractions will involve sensitive data, sexualities, HIV etc. The steering group Chair said there are restrictions on sensitive codes in place but the standards around these are old, from 1998. An example is Secondary Use Service (SUS) lets the data flow with the sensitive item included. The Standardisation Committee for Care Information (SCCI) are working to come up with an up to date list of sensitive data items.

2.2.10 A member suggested there are two aspects to sensitive codes (whether it refers to the identity of a patient or practitioner or whether it refers to a characteristic of a patient such as a sexually transmitted disease), a review of such codes and then how they will be managed.

2.2.11 The steering group Chair stated SUS automatically removes identifiers for data with sensitive codes. However the Chair suggested he take the issue of removal of identifiers away from the meeting and report back on how such codes are handled. Current understanding is that records with sensitive codes and identifiers is that the identifiers are removed on landing.

2.2.12 A member asked whether CPRD continues to share patient level data to the US and other countries outside the EU. The sub group Chair stated that section 5 sets out some outstanding issues beyond the scope of the paper, included in which is whether re-use contracts are effective.

2.2.13 The member fromCPRD stated it is currently undertaking a wide ranging review of all

of its IG processes.

2.2.14 The steering group Chair asked if Alan Hassey has reviewed the paper, particularly in regard to section 4.4. The sub-group Chair stated the paper has been reviewed a number of times by Alan Hassey but would raise the specific section with him again.

2.2.15 A member asked about section 3.4 – Patient Objections whether such objections override S251 data extractions. A steering group member advised that S251 does not override patient objections since a standard condition of s251 is that all patient objections must be respected..

2.2.16 A member asked if GPES IAG still existed. Another member stated it does but not for much longer as HSCIC want to rationalise the process of governance of release of data and that such bodies, such as GPES IAG, would no longer be in operation. The steering group Chair confirmed the HSCIC does want to rationalise such bodies.

2.2.17 A member asked if any new body put in place by HSCIC whether it would have patient representation as DAAG doesn't. The steering group Chair took an action to check the new groups Terms of Reference and will report back to the group. Another member stated he was not aware of the new group but stated DAAG process is now very stringent. Another member stated that rationalising data releases is okay but Data Controllers need to be clear on the purposes for which data are to be used and by whom so that they can inform patients.

2.2.18 The steering group Chair in summing up the Context paper discussion stated the paper is acceptable but a number of comments need addressing.

The question on releases of identifiable data needs to be clearer in the paper, sentence on page 12/13 section 4.4, para, needs to be clear on pseudo data outside of the EU. The sentence needs to reflect DAAG approvals to manage release of identifiable data. The sub-group Chair was asked to confirm if Alan Hassey/DAAG are happy with section 4.4 The sub-group Chair asked if the steering group Chair could set out what needed checking and that he would look to achieve ratification remotely.

Action No. 2: Steering group Chair to investigate whether removal of identifiers with sensitive codes is undertaken automatically in SUS.

Action No. 3: Steering group Chair to review the new Terms of Reference for the new (currently without a title) HSCIC advisory group has a patient representative role and report to group.

Action No. 4: Standards & Terminology sub-group Chair to contact DAAG about section 4.4 and confirm approval of the sentence on data outside of the EU. Once approval confirmed to then seek ratification of Context paper outside of the steering group meeting.

3.0 Pseudo @ Source sub-group update

3.1 The Chair of the sub-group presented the sub-group's Progress Report outlining following deliverables from the sub-group.

3.1.1 PS04 – This has been sent to sub-group and steering group for review and has now been sent to suppliers for completion. The Review's project manager updated the steering group that PS04 is in two parts, a questionnaire sent to suppliers identified in an earlier deliverablerPS03 and a Market Assessment. Both parts, of PS04, have been sent to sub-group and steering group for review.

3.1.2 A steering group member asked if the definition of 'pseudonymisation at source' will be used in the supplier questionnaire. There followed a discussion on what is meant by pseudo at source, with agreement reached that it means the data controller undertakes the pseudonymisation before the data are shared with a third party and doesn't refer to data shared with a third party which are subsequently pseudonymised. The chair of the Standards & Terminology sub-group stated that the definition of pseudo at source is the subject of his sub-groups Vocabulary paper. It was suggested that examples of pseudo at source should be provided in the Vocabulary paper and the S&T sub-group Chair agreed to undertake this and took an

action to circulate the paper with the proposed changes.

The Pseudo @ Source Chair agreed that PS04 paper should have the pseudo at source definition on the top of the PS04 questionnaire. The Review's project manager to arrange reissue of PS04 to suppliers.

3.1.3 PS05 – Pros, Cons & Barriers. This deliverable was presented to the steering group for information only. However comments were being requested for the themes (categories) shown in the paper. These are intended to categorise the circa 272 comments as a way of conducting an analysis of comments from stakeholder events against each of the three models for pseudonymisation

3.1.4 A steering group member asked what was said at the events as without this context it is difficult to understand the comments provided. In addition it would be helpful to know where and who the comments came from.

3.1.5 A steering group member who attended one of the events mentioned that ATOS was as a supplier was discussed at the event and asked whether their contract with HSCIC was still in place. The steering group Chair said this came up on a Data Linkage & Data Quality sub-group call and that he had requested clarification on whether the existing contract with ATOS was being renewed.

3.1.6 Another steering group member asked how the themes came about. The P@S sub-group Chair advised that the themes at the industry event held at TechUK offices were clear but was not sure on how they were developed for the further events. The Reviews project manager stated these were generated by the internal HSCIC team working in behalf of Pseudo @ Source sub-group and comments were being requested on the proposed themes.

3.1.7 Another steering group member commented that it is difficult to extrapolate anything from the free text comments shown in PS05 deliverable. This member suggested that the HSCIC should look to contract an independent qualitative researcher.

3.1.8 The steering group Chair stated there were two responses to the above suggestion. Qualitative evidence is expected to be deliverable as part of the sub-groups work. However obtaining an independent qualitative researcher would be a challenge.

3.1.9 A steering group member suggested the methodology of the approach taken in PS05 needs to be made clearer and then it should be tested. The P@S sub-group Chair agreed and stated the internal team would look to provide the detail behind approach taken.

3.1.10 The Review's project manager outlined the current status of Psuedo@Source deliverables:

PS06 - Impact of pseudonymisation on interoperability standards. Has had one round of sub-group review and comments received need to be reflected in a new version for second round review.

PS07 – Implications of pseudo at source on Information Governance & Transparency. Has had one round of sub-group review and a number of comments received which are currently undergoing internal team review need to be reflected in a new version for second round review.

PS11 – Relative security benefits & risks of different pseudo models and the PS13 – **Summary of other organisations ability to pseudonymise data**.

Both of the above deliverables are undergoing internal team development. Draft versions are expected to be issued for sub-group review late March or early April.

3.1.11 Another steering group member, in responding to para 3.1.3 about PS05, commented that there appears to be not enough input from clinicians and data subjects in the sub-groups deliverable.

3.1.12 The steering group and sub-group Chairs agreed that the Review's Interim Report and the Review's final report should look to engage clinicians.

3.1.13 A steering group member suggested sending the three pseudonymisation models from the Interim Report as a statement on what the Review is doing and sends to clinicians for their review.

3.1.14 Another steering group member raised the concern that this would open up a lot of questions that would be difficult and take to respond to. The steering group member making the suggestion of a statement to clinicians suggested the steering group should consider how engagement with clinicians should be undertaken.

3.1.15 The steering group Chair stated that patient's engagement was considered earlier in the Review but was not appropriate at that time but perhaps it was now appropriate to consider as the steering group has a more considered viewpoint on pseudonymisation. The P@S sub-group Chair agreed and stated contacting clinical groups would be looked at.

3.1.16 A steering group member suggested a workshop for patient feedback; perhaps the National Association of Patients (NAP) should be contacted. Another steering group member suggested that NAP has a particular viewpoint and that any approach needs to consider the objectives of the Review's work. The steering group Chair asked the Review's project manager to discuss with HSCIC Comms team about contacts with patient representative groups.

Action No. 5:   Review's project manager to investigate contacts with patient representative groups that are available through HSCIC Comms.

4.0   Data Linkage & Data Quality sub-group update

4.1   The sub-group Chair presented the DLDQ03 paper for information.

4.1.1 This has undergone several sub-group reviews and whilst it is a latest draft for information it has not yet received sub-group approval. However the paper has developed sufficiently enough that subject to steering group comments the paper should come back to the steering group for ratification.

4.1.2 A steering group member commented that the level of NHS No in some of the datasets, detailed in DLDQ03 Data Quality paper, for example MH with 98% were not was not as high as in other datasets.

4.1.3 The sub-group Chair commented that the effectiveness of obtaining NHS No. varies depending on the different service settings.

4.1.5 No other comments were raised and the sub-group Chair said the paper should be updated with version and title before sending to sub-group approval and presenting to the next steering group.

4.1.6 The sub-group Chair updated the steering group on progress with DLDQ04 – Theoretical paper on data linkages. This has undergone substantial development and is currently out with the sub-group for review. It was stated that the paper will need several reviews rounds before being presented to steering group.

5.0   February Steering Group Minutes

5.1   The minutes for February's steering group were reviewed. The only comment received was to correct the name of the group's patient representative before publishing on the Review's website.

6.0   Review of Actions

6.1   Action 41 – The steering group Chair updated the group on this action. There is a MACS (bulk update service) which fills in items needed in datasets e.g. DOB, NHS No., NHS orgs and Las, etc. and then sends back to the originator the completed dataset.

Action closed.

6.2   Action 44 – This was agreed as closed following the update on the sub-groups work provided in the meeting.

7.0   Standards and Terminology sub-group update

7.2   The Standards and Terminology sub-group continued it's update from **2.2.18** following a break in the sub-groups update due to the meeting's quorum requirements and to accommodate the Pseudo @ Source update requirement to finish early in the meeting.

7.2   The sub-group Chair presented the Pseudonymisation Legislation Reference List v0.2 to the steering group

    7.1.1   The paper was presented for steering group review prior to the meeting. Two sets of comments have been received, one for a steering group member and the other from a member of CAG. Subject to no other comments being received the sub-group Chair advised the group he would be updating the paper and sending a new version round for a further review before presenting back to the April steering group.

8.0   Next Stage Report

8.1   The Review's project manager presented a proposed structure for the Review's Next Stage Review.

    8.1.1   The steering group Chair stated the paper needs to gain commitment to completion of sub-groups deliverables. A steering group member stated that meetings are proving difficult to track as a number had been cancelled.

    8.1.2   The steering group Chair asked the Review's project manager to communicate the latest view of meeting dates to all steering and sub-group members. In addition to table a number of meeting dates for the steering group over the coming months and consider organising as both face to face and by teleconference calls.

Action No. 6:   Review's project manager to investigate contacts with patient representative groups that are available through HSCIC Comms.

9.0   AOB – No items of other business were raised.

10.0   Next Meeting – To be confirmed by email.