

Draft Meeting Minutes

Pseudonymisation Steering Group

Meeting 4, Tuesday 9th September 2014

Skipton House, London, SE1 6LH

(Amended and Ratified at 7th October Steering Group)

Attendees:	Role	Organisation
Antony Chuter	Patient Representative	
Andy Collett (in attendance from Agenda 5)		IBM
Harvey Goldstein	Academic Expert on Data Linkage	University College London & University of Bristol
Wally Gowing	Pseudonymisation Advisor	
Ian Herbert	Primary Health Care IT Specialist Group and GP Extraction Service Independent Advisory Group (GPES IAG) Member	British Computer Society
Julia Hippisley-Cox (dial in)	Academic Expert on Data Linkage and EMIS National User Group	Nottingham University
Max Jones	Director of Data & Information Services and Pseudo Review Chair	HSCIC
Sean McPhail	Senior Information Analyst	Public Health England
John Parkinson (dial in)		Clinical Practice Research Datalink
Chris Roebuck	Director of Benefits and Utilisation and Review Co-ordinator	HSCIC
Matt Spencer	Pseudo Review Project Manager	HSCIC
Marc Taylor	Observer	Confidentiality Advisory Group
Alastair Williams (in attendance from Agenda 5)		IBM
James Wood (dial in)	Head of Infrastructure Security	HSCIC

Apologies

Paul Cundy	General Practitioners Committee	BMA
Xanthe Hannah	Observer	NHS England
Alan Hassey		IIGOP
David Ibbotson	Care.data Programme Head	HSCIC
Phil Koczan	GP	RCGP & Health Informatics Group
Geraint Lewis	Chief Data Officer (Observer)	NHS England
John Madsen	Head of Productivity & Efficiency	HSCIC
Dawn Monaghan	Observer	Information Commissioners' Office
Nicholas Oughtibridge	Leading on Code of Practice for Confidentiality	HSCIC
Daniel Ray	Head of NHS Chief Information Officer Network	University Hospital Birmingham
Hashim Reza	Consultant Psychiatrist and Mental Health Information expert	Oxleas Trust
Eve Roodhouse	Director care.data	HSCIC
Ralph Sullivan	GP	RCGP

1. Welcome and Introductions

- 1.1. Colleagues were welcomed to the fourth meeting of the HSCIC's steering group on pseudonymisation. The Chair thanked the group for its contributions over the past weeks.
- 1.2. Introductions were completed. It was noted that two attendees from IBM would join in the later stages of the meeting to present on Agenda item 5.
- 1.3. Anthony Chuter advised the group that he doesn't represent PAIN UK on the steering group as shown by the agenda and previous month's minutes. The reference to PAIN UK is to be removed.

2. Review of minutes/actions

- 2.1. The minutes and actions of the 13th August Steering group were reviewed with comments raised as follows:
- 2.2. **Action 1 – Membership for steering group.** A number of contacts have been made and new members would be joining the group such as a representative from TechUK and from the Social Services sector. The action was closed as membership was considered to now be sufficient but members were encouraged to provide any suggestions at future steering group meetings.

- 2.3. A member of the group asked whether there should be an action to look at funding for focus group involvement in the review.
- 2.4. The chair stated that there are already a number of existing vehicles for public engagement on topics ranging from not just pseudonymisation but also the wider information governance debate. For example an event held on July 1st was attended by over a hundred stakeholders from various bodies including patient advisory groups.
- 2.5. It was noted by a member that it is difficult to achieve effective public engagement for what is a difficult topic of pseudonymisation. Another member stated that presenting pseudonymisation as a subject is difficult and that documentation on the topic is not easy to digest for the general public. In addition comments were made that it has to be made clear why the review is being undertaken as pseudonymisation is not the only way for the HSCIC to control patient data securely.
- 2.6. The chair proposed that the need for public engagement in the review is looked at later in the year when the outputs from other stakeholder engagements will be available.
- 2.7. For the August minutes **Section 6 – Reversibility/Irreversibility of Pseudonymisation** a group member raised concern that the assertions could be read as being the views of the group rather than the views of an individual within the group. .
- 2.8. The chair stated he believed the minutes reflected what was discussed and the fact that this discussion represented individuals' statements rather than the group's views would be stated in the September minutes. He noted that the Standards & terminology sub-group would be referring to points raised in Section 6 of the August minutes as part of its update to the group in agenda item 4 in today's meeting.
- 2.9. It was agreed, by a number of members, that definitions, of reversibility and irreversibility, as well as others are key to the groups work and welcomed the fact that Standards & Terminology sub-group were looking to undertake this.
- 2.10. Following this discussion, some amendments were proposed to section 6.1
- Greater clarity on the point that was raised around reversibility of pseudonymisation in cases where clinicians may need to reidentify patients
 - To be clearer on the intent to defer the subject of the sub-section to the Standards & Terminology sub-group to report back to the steering group on this topic.
 - Alongside this, there have been some paragraph formatting revisions.
- 2.11. The August minutes, once the amendments are made, are therefore ratified.

3. HSCIC Update

- 3.1. The chair commented that future meetings of the steering group are expected to focus more on sub-groups progress and the presentation of papers for review by the steering group.

3.2. The chair outlined the recent initiative to provide communications of the work in the HSCIC Data and Information Analysis directorate which may be of use to the steering group. The most recent of which provides an update on the directorate's work and in particular the Data Sharing Agreements (DSA).

Action Point: Provide a copy of the Data Bulletin to review group.

3.3. A member asked if DSAs are to come under the remit of the Pseudonymisation Review.

3.4. The chair advised that DSAs have been through a number of reviews and that the Pseudonymisation Review is not expected to review them. However it would be useful for the output of the reviews, which include details on penalties being set out, be made available to the group. The view of the chair was that the new DSA arrangements were an improvement on the previous regime for authorising data releases.

Action Point: Circulate the output of the DSA to the Review group for information.

3.5. Chair stated that the HSCICs position is to get to a point where clear guidelines and processes are in place to support 'per purpose-per customer' use of its data.

3.6. A member commented that it is important to make available information on what organisations receive and this should be reflected in any HSCIC contracts.

4. Sub-group Updates

4.1. Standards and Terminology update – Wally Gowing

4.1.1. The membership of Standards and Terminology sub-group is now established with latest member Sean Kirwan, currently working on a DH Glossary, joining the sub-group in August.

4.1.2. The sub-groups work programme has been defined with milestone planning still ongoing the intention is to present the sub-groups Terms of Reference for review and approval at October's steering group meeting.

4.1.3. The sub-group has started working on two areas of its work programme:

- 'A Vocabulary for the Review' – An agreed list of terms and definitions to be used within the Pseudonymisation Review.
- 'Context of Pseudonymisation' – To clarify the wider context in which pseudonymisation would be applied in response to the issues around pseudonymisation highlighted by John Parkinson – CPRD at August's steering group meeting.

4.1.4. An initial draft of the 'Vocabulary' was made available to the steering group but requires finalising before being sent for formal review by the steering group. The purpose is to have a set of definitions for use by the review group. It should be noted that some terms listed do not have a source so the sub-group will be asking for review comment on this issue and the definitions proposed by the next steering group meeting.

4.1.5. Members in reviewing the draft Vocabulary made a number of comments.

- It would be useful for the sub-group to state which definitions are important to focus on.
- The vocabulary is presented in long list. It would be helpful to organise the around a hierarchical view to aid comment and usage. For example organising terms relating to pseudonymisation, terms relating to techniques and terms relating to legal sources would be helpful.
- Encryption was noted as missing from the list. This is a critical area which national programmes in HSCIC are looking at.
- The review should be doing a definition of Information Governance terms, as the subject is large, however some of the terms should be regarded as definitive as they are already embedded in statutory law. In addition the Confidentiality Advisory Group (CAG) has an interest in this as it has done some parallel work which should be co-ordinated with the Standards & Terminology sub-groups work.
- Key Management was noted as missing from the list – It is a subtle term but important to have a definition that the review group can use.
- The Vocabulary should be interested in the properties of the terms however it should not concern itself with ‘how it is done’ for example Algorithms should not be looked at but the definition of an algorithm needs documenting.

4.1.6. The chair noted the progress made by the sub-group, on the Vocabulary, and suggested it should be made available to CAG when it’s in a working version. Also wider application to other sub-groups needs to be factored into the S&T group output.

4.1.7. The sub-group chair updated the steering group on the creation of a ‘Context of Pseudonymisation’ paper.

4.1.8. The paper seeks to provide a context for pseudonymisation that answers the issues raised at the August steering group meeting concerning the use of pseudonymisation and how pseudonymised records containing event data would still be susceptible to attack.

4.1.9. The paper, in draft form, has been quality assured by Alan Hassey and circulated to sub-group members for comment. It covers the following areas:

- The users of the data and the uses to which the data are put
- Legally processing patient level data beyond the HSCIC
- Appropriate technical, organisational and legal measures
- The context for undertaking HSCIC pseudonymisation
- Implications for the HSCIC on the release of HSCIC pseudonymised data.

4.1.10. The sub-group will continue to review the draft paper during September so an agreed version can be presented at the next steering group meeting.

4.2. Data Linkage and Data Quality update – Chris Roebuck

- 4.2.1. The Terms of Reference for the sub-group has been drafted and comments received from subgroup members. A final review is underway before submitting to steering group.
- 4.2.2. A number of research studies are proposed to be undertaken to look at issues around levels of data linkage, use of pseudonymisation on linked data and the resultant data quality issues.
- 4.2.3. A protocol has been written to look at linking CPRD data with HES data in order to answer questions on data linkages. The sub-group is looking to obtain required resources to undertake the study, these resources may be from university researchers or from with HSCIC.
- 4.2.4. The Chair highlighted the importance of a process that is transparent and in line with procurement rules if resource is to be brought in from outside the HSCIC.
- 4.2.5. The proposed data sets, CPRD and HES, will allow the sub-group to look at the impact of linked data when pseudonymisation is applied before and after linking.
- 4.2.6. The quality of the linked data will need to be looked at. Whilst it will be easy to identify differences in which records link and do not link under different algorithms, there are likely to be challenges in gaining a definitive view on which records should and shouldn't link to compare against.

4.3. Pseudonymisation at Source update – James Wood

- 4.3.1. A Terms of Reference has been drafted for the sub-group and once agreed will be presented to the steering group for approval.
- 4.3.2. Initial meetings have been held and a number of questions of the groups work have been raised.
- 4.3.3. The sub-group asked the steering group if it is correct to exclude Pseudonymisation at Central from its work programme.
- 4.3.4. The steering group chair stated that the pseudonymisation at source and hybrid models should be the group's initial priority for reporting back to the steering group. However, it was stated that there would be a need to compare with the central pseudonymisation model, so that this should be explored in due course.
- 4.3.5. It was noted that pseudo at source model has an impact on security and their attendant costs.
- 4.3.6. The sub-group needs to consider the question, of which model to work on, and the impact against the interim report objectives and return back to the steering group for further guidance.
- 4.3.7. The pseudo at source sub-group asked the steering group whether it should look at general requirements first or whether it needs to look at specific requirements in detail.

4.3.8. The steering group view was that the sub-group should look at starting from a simple baseline of requirements first. The 5 per cent of requirements, which might be difficult, should be looked at later.

4.3.9. The sub-group chair agreed and will add the work programme for the sub-group.

4.3.10. The sub-group chair updated steering group on the setting up of an industry workshop day to obtain market views on the sub-groups objectives. The workshop will be organised through TechUK and expected to take place late October.

4.4. The steering group chair in noting the progress made by sub-groups stated that activity levels need to increase in order to provide the steering group with the material and evidence base to make recommendations to HSCIC EMT sooner rather than later.

5. AOB

5.1. The patient representative on the steering group raised with the chair the issue of payment of the representative's involvement had not been resolved. The chair responded that the individuals' involvement was important to the steering groups work and that the issue should be expedited internally within HSCIC and to achieve a resolution in the next couple of weeks.

5.2. There were no other items raised.

6. Presentation by IBM

A presentation on 'A Banking Sector view of Data Management' was presented by Alastair Williams – IBM.

The presentation has been made available to steering group members prior to today's meeting.

Next meeting: Tuesday 7th October 11.00pm to 13.00pm at Skipton House, London.