Draft Meeting Minutes

HSCIC Pseudonymisation Review Steering Group

Meeting 5, Tuesday 7th October 2014

Skipton House, London, SE1 6LH

For ratification at next Steering Group meeting

Attendees:	Role	Organisation
Antony Chuter	Patient Representative	
Paul Cundy (by dial in)	GP	GP Committee & BMA
Mark Elliott (via video conference for agenda item 5)	Interdisciplinary Social Scientist / PGR Director - Cathie Marsh Centre for Census and Survey Research	Manchester University
Harvey Goldstein	Academic expert on Data Linkage	University College London & University of Bristol
Wally Gowing	Pseudonymisation Advisor	
Xanthe Hannah (by dial in)	Observer	NHS England
Ian Herbert (by dial in)	Primary Health Care IT Specialist Group and GP Extraction Service Independent Advisory Group (GPES IAG) Member	British Computer Society
Julia Hippisley-Cox (by dial in)	Academic expert on Data Linkage and EMIS National User Group	Nottingham University
David Ibbotson (by dial in)	Care.data Programme Head	HSCIC
Phil Koczan (by dial in)	Health Informatics Group member	RCGP
Sean McPhail	Senior Information Analyst	Public Health England
Richard Pantlin	Social Services representative	Oxford Social Services
John Parry	Medical Director	TechUK
John Parkinson		Clinical Practice Research Datalink
Chris Roebuck (Acting chair)	Director of Benefits and Utilisation and Review Co-ordinator	HSCIC
Matt Spencer	Pseudo Review Project Manager	HSCIC
Marc Taylor	Observer	Confidentiality Advisory Group

| James Wood (dial in) | Head of Infrastructure Security | HSCIC |

Apologies

Max Jones	Director of Information & Analytics / Pseudonymisation Review Chair	HSCIC
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

1. Welcome and Introductions

1.1. Colleagues were welcomed to the fifth meeting of the HSCIC's steering group on pseudonymisation. The Acting Chair thanked the group for its contributions over the past weeks and welcomed two new members; John Parry representing TechUK and Richard Pantlin representing Social Services sector.

1.2. Introductions were completed. It was noted that Mark Elliott – Manchester University would join the meeting via video conference at 12.00 to present on agenda item 5.

2. Review of minutes/actions

2.1. The minutes presented to the steering group for ratification were for September meeting and a re-drafting of section 6 from August meeting.

2.2. The minutes of the 9th September Steering group were reviewed with comments raised as follows:

2.2.1. A member stated that section 4.1.5 / 4th bullet point was incorrect and should be amended to remove the word **'not'** from the section. It was further stated that CAG was referenced incorrectly in this paragraph and the reference to CAG should be amended to state that CAG is doing some work on definitions and it should be aligned with the working of the steering group wherever possible.

Action No. 1: The September minutes section 4.1.5 to be amended as outlined in 2.2.1

2.3. The re drafted minutes from section 6 of the 13th August meeting was reviewed by members.

2.3.1. A member queried the reference to Risk Stratification in section 6, of August minutes, but which is not in the Standards and Terminology sub-groups 'Vocabulary' paper.

2.3.2. The chair of the Standards & Terminology sub-group said that the 'Vocabulary' paper is currently undergoing sub-group review and he would ensure that the term of risk stratification is included.

Action No. 2: That the term of risk stratification be included in the Standards & Terminology sub-groups 'Vocabulary' paper.

2.3.3. The Chair therefore stated the September, with amended section 4.1.5 as stated in above 2.2.1 minutes note, and redrafted August minutes (section 6) were approved and would be published on the Review's website.

2.3.4. The Chair also stated that sub-groups need to provide the evidence base against approved work plans and ToRs. Such evidence would enable the steering group to deliver on the Interim Report to provide recommendations to the HSCIC EMT.

2.4. The actions from September's meeting were reviewed and a number were agreed as closed. It was noted action number 13 – Circulate copies of DSA report remains open.

3. **Standards & Terminology sub-group update**

3.1. The Terms of Reference for Standards & Terminology sub-group has been sent to members for ratification at today's meeting.

3.1.1. The chair of the S&T sub-group gave an overview of the ToR and how members had approved it via sub-group meetings.

3.1.2. One member in stating that the ToR covers a large amount of work and asked whether the Steering Group should advise on priorities.

3.1.3. The sub-group chair in agreeing that priorities hadn't been discussed asked the steering group what the timeframes for the work was expected to be. It was stated that some of the deliverables would be continued to be developed with an expected presentation to steering group in January 2015.

Action No 3: Chair of Standards & Terminology to propose prioritisation of the sub-groups deliverables and present this to the next Steering Group meeting.

3.1.4. Another member of the steering group raised the need for consistent naming conventions to be used across documents presented to the group.

Action No 4: The Review's project manager to ensure consistent naming conventions of documents presented to group

3.2. Following this discussion, the ToR for Standards & Terminology sub-group was ratified by the steering group.

3.3. The sub-group chair continued updating members on latest position of the 'Vocabulary' paper. Whilst this paper was not an agenda item and therefore had not been presented to the steering group the sub-groupo chair felt it was important to update the group on recent changes made following the September meeting.

3.3.1. The revision made to the Vocabulary , following comments made in September's meeting, were to restructure the format into following hierarchal structure:

- Legal

- Formal to cover policy and formal guidance

- Widely used

- Working definitions from the S&T sub-group

3.3.2. These revisions, whilst reflecting comments made in September's meeting, raised concern that the Standards & Terminology chair didn't wish to lose some of the terms on the list e.g. weak pseudonymised, even if we are proposing that they are not used, as this in itself is important information.

3.3.3. A steering group member said it is useful to have a section for terms which are deprecated and 'weak pseudonymised' is one example.

3.3.4. Another member, in agreeing that deprecated terms should be noted, said that that it would be important to note 'who' deprecated the terms used.

3.3.5. The member who raised the point about use of deprecated terms further commented that inclusion of such terms as well as the deprecated terms themselves is common practice for glossaries and vocabularies.

3.3.6. Further comments on the structure of 'Vocabulary' paper were raised, in particular the need to make a distinction between 'Pseudo before Linkage' and Pseudo after Linkage' terms.

3.3.7. The standards & terminology sub-group chair agreed in general with the comments raised and would consider the points when revising the current draft version.

3.3.8. The steering group Chair said both terms are relevant to the review's work and should be included in the 'Vocabulary' paper.

3.3.9. A steering group member stated that relevance of such terms, as outlined in the Vocabulary, can depend on the audience. The member also said Pseudonymisation, as a term, is not in common usage and that documents on the subject can take a considerable amount of time to absorb terms used in such documents.

3.3.10. The steering group chair stated it is important that terms be as simple as possible but the language needs to be precise and hoped the restructured Vocabulary will aide discussion within the review group. In certain instances there will be a further step once a consistent definition is agreed in communicating it to a wider audience.

3.3.11. It was also pointed out that the term "deprecated" is itself not particularly accessible to a wide audience.

Action No. 5 – The chair of Standards & Terminology sub-group to ensure that there is a plain English explanation of deprecated in the document

3.4. The sub-group chair introduced the 'Context for Pseudonymisation' paper which was sent to the steering group for information.

3.4.1. The 'Context' paper came out of August's steering group in which John Parkinson – CPRD raised a number of points about the release of data, event data and patient data.

3.4.2. The 'Context' paper has been developed in respect of Pseudonymisation for HSCIC and not system wide. It is intended to be clear around what other controls need to be employed alongside pseudonymisation . But the sub-group chair thought there that there are wider issues to consider and would the steering group wish to comment.

3.4.3. A steering group member stated that the legal terms used could be a struggle for many people. Also could not see any reference to Anonymisation. It is important to note that Pseudonymisation is just one technique and the paper should reflect this.

3.4.4. Another member raised the issue of other organisations using HSCIC data. The paper needs to be clear what arrangements are in place if HSCIC data is sent to third party organisations around their onwardly transferring the data to another organisation.

3.4.5. It was stated that data sharing contracts specify whether such onward sharing of data is authorised and if so under what conditions.

3.4.6. The steering group Chair stated the objective of the Review is to consider where HSCIC wants to be and not to look back at the past and any issues which occurred.

3.4.7. A steering group member stated the importance of having contracts in place for when HSCIC data is used. These contracts are clear what security and usage of the data is possible and should not just talk about 'release of data' but the implications of anyone attacking the data and should ensure pseudonymised data is not released incorrectly.

3.4.8. Another member asked where in the process of pseudonymisation should contracts be in place. Should it be before or after HSCIC receives the data?

3.4.9. Another member stated it needs to be clear that contracts and identifiable data owners should police the relevance of data whether pseudonymised or not.

3.4.10. Another member stated that both organisations responsible for the release of data and organisations receiving the data have obligations under the DPA to process the data lawfully.

3.4.11. The sub-group chair thanked steering group members for comments raised and advised further iterations will be issued for sub-group review with an expectation to present the paper to the November steering group meeting.

4. **Data Linkage & Data Quality Sub-group update**

4.1. The Terms of Reference for the sub-group was presented to steering group members for ratification at today's meeting.

4.2. The sub-group chair outlined the main points in the ToR which sets out what the sub-group will and will not be looking at.

4.3. A steering group member suggested that reference to an earlier workshop on data linkage be referenced in the sub-groups ToR. The chair of the sub-group asked that the information on the workshop be sent to the chair for consideration.A steering group member suggested an amendment to the ToR qualifying the intended scope of data linkage.

Action No. 6 – Data Linkage & Data Quality sub group chair to amend Terms of Reference for the point raised in item 4.3 of October's steering group minutes

4.4. Subject to this amendment, the group approved the sub-groups Terms of Reference.

4.5. Another steering group member asked whether sub-groups ToRs would be made available on the Review's website. The Chair stated that this is the intention.

4.6. The sub group deliverable of a study comparing linkage quality before and after pseudonymisation was discussed. A concern was expressed that the current document describing the study may be misinterpreted as implying that CPRD receives identifiable data, when in actuality only pseudonymised data are received.

Action No. 7 – The DL & DQ CPRD/HES protocol document to be amended to make it clear CPRD only receives pseudonymised data.

4.7. A question was raised on whether it would be useful for steering group members to highlight other flows of identifiable data for which a study could be constructed to compare linkage quality for pseudonymisation on identifiable and pseudonymised data. The chair replied that it would be useful and feasibility of such studies could be considered on the basis of available resource, cost and Information Governance requirements.

5. **Presentation on Pseudonymisation and the Anonymisation Decision Making Framework**

Mark Elliott – Manchester University presented, via video conference, on the agenda topic. The presentation material was emailed to steering group members prior to the meeting.

The presentation was well received with a number of questions raised to Mark. These were responded to by Mark along with a commitment to provide the Review with an early sight of the 'Open Source – Best Practice' book referenced in his presentation. The Chair thanked Mark for his presentation saying the subject was relevant to the Review's work and looked forward to seeing the early drafts of the 'Open Source' book.

Post Presentation Note: A steering group member mentioned that Mark is presenting at the Royal Statistical Society venue on 13th November and if members were interested in attending they need to book via the RSS website.

Action No. 8: Members to access the RSS website for further details of the November event.

Action No. 9: Mark Elliott to provide any early draft versions of 'Open Source – Best Practice' book for the steering group when available.

6. Pseudo @ Source sub-group update

The chair of the sub-group James Wood attended the meeting by dial in. However due to the agenda running late he could not stay to provide his update to the steering group.

Julia Hippisley-Cox provided a verbal update on James's behalf.

6.1. Terms of Reference in draft, is currently being reviewed by James Wood. This is expected to be available in the next week for Steering Group to ratify.

6.2. An industry workshop day is being organised through TechUK for late November. TechUK are to consider potential organisations to attend the workshop and provide a list to James for approval.

7. AOB

The Chair asked members for any other business.

7.1. A member suggested it would be useful for Confidentiality Advisory Group (CAG) to have sight of what sub-groups are doing. The member stated Pseudo @ Source sub-group would be of particular interest to CAG.

7.2. Another member highlighted that there were a range of perspectives within the group and sometimes this led to disagreements without it being clear what was driving them. The member asked if there was a need for a facilitated session for the Review members to articulate their perspectives on pseudonymisation. The suggestion was made as there were differing and wide range of views being represented by the Review and it would be helpful to know what everyone understood about the subject of Pseudonymisation. It would also be useful to know the starting point of members' knowledge of Pseudonymisation.

7.3. Another member suggested a one hour session to focus on 'terminology' would be useful as the member's view was that 80% of disagreements were around this subject.

7.4. The Chair highlighted that the group had purposefully been assembled to incorporate a broad range of perspectives on this important topic. He suggested that it would be sensible to wait for the Standards & Terminology sub-groups paper on 'Vocabulary' before deciding whether a facilitated session was necessary. However the Chair asked that members send, around the group, their views on holding a facilitated session as described in 7.3.

Action No. 10: Members to send round the steering group their suggestions on how to bring to the fore members' different perspectives and get to the heart of what is causing differences of opinion.

7.5. The chair of the Standards & Terminology sub-group said the discussion had been helpful in getting the range of views known and would look to revise the 'Vocabulary' paper to meet the challenge.

7.6. A member asked if further presentations would be a feature at future steering group meetings as their inclusion on the agenda meant that the review's core business was often rushed and the efforts of the meeting diluted. Could such presentations be

recorded for members to view in their own time? Whilst there was general agreement on this point it was noted that today's presentation was considered to be useful to the review's work.

7.7. Another member suggested a future agenda item to focus on piloting of proposals. The Pseudo @ Source sub-group agreed to consider examples where this could be explored.

7.8. The Chair, in closing the meeting, briefly presented the work plan showing the deliverables of the sub-groups for information. Members were asked to review and to provide comments to the sub-groups and for the sub-groups to review before presenting to the next steering group meeting.

Action No. 11: Members to review the workplan and provide comments to sub-group chairs as soon as possible.

Action No. 12: Sub-group chairs to undertake a review of comments recieved and to review deliverables expected in the workplan and present to the next steering group a final list of deliverables for ratification.

Next meeting: Wednesday 5th November 12.00pm to 14.00pm at Skipton House, London.