

## Meeting Minutes

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### Pseudonymisation Steering Group

Meeting 1, Friday 2 May 2014

Skipton House, London

Ratified at 3<sup>rd</sup> July 2014 Steering Group meeting

**Present:**

Sean McPhail (part) (in place of Chris Carrigan)	User of HSCIC Data	Public Health England
Antony Chuter	Patient Representative	Pain UK, Pain Charities/Research
Paul Cundy (dial in)	Representing British Medical Association (BMA)	General Practitioners Committee and BMA
Harvey Goldstein	Academic Expert on Data Linkage	University College London & University of Bristol
Alan Hassey	HSCIC IG lead and member of Independent Information Governance Oversight Panel	HSCIC
Ian Herbert (part)	Primary Health Care IT Specialist Group and GP Extraction Service Independent Advisory Group (GPES IAG) Member	British Computer Society
Julia Hippisley-Cox	Academic Expert on Data Linkage and EMIS National User Group	Nottingham University
Phil Koczan	Representative of the Royal College of GPs and member of the Health Informatics Group	GP, RCGP
Xanthe Hannah (in place of Geraint Lewis)	Chief Data Officer	NHS England
John Madsen	Head of Productivity and Efficiency	HSCIC
John Parkinson	User of HSCIC Data	MHRA, Director of CPRD
Daniel Ray	Head of NHS Chief Information Officer Network	University Hospital Birmingham
Hashim Reza (dial in)	Consultant Psychiatrist and Mental Health Information	Oxleas Trust

expert

Chris Roebuck	Director of Benefits and Utilisation and Review Co-ordinator	HSCIC
Eve Roodhouse	Care.data Programme Director	HSCIC

**In attendance:**

Natasha Dunkley		Confidentiality Advice Group
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Wally Gowing	Pseudonymisation Expert	
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Nicholas Oughtibridge	Leading on Code of Practice for Confidentiality	HSCIC
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**Apologies**

Dawn Monaghan (observer)	Group Manager	Information Commissioners' Officer
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Ralph Sullivan	HSCIC Primary Care Lead	HSCIC
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James Wood	Infrastructure Security Manager	HSCIC
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## 1. Welcome and Introductions

- 1.1. Colleagues were welcomed to the first meeting of the HSCIC's steering group on pseudonymisation. The importance of the question of pseudonymisation was outlined. The Chair conveyed that people had been selected for the group based on the expertise they would bring and were chosen to represent a diverse set of perspectives around pseudonymisation.
- 1.2. The need to engage with the public on pseudonymisation in language that is meaningful was noted.
- 1.3. A question was raised around additional representation on the group and it was suggested that subject matter experts could be invited to particular meetings on which their input was relevant and that the group would commission work from outside it. It was suggested that someone from the administrative data task force could be invited to join the group.

**Action – CR to review membership list for possible additions based on feedback from group**

## 2. Review of terms of reference

- 2.1. A number of amendments were suggested to the draft terms of reference.
- 2.2. It was suggested that the terms of reference and documentation generally should do more to fit pseudonymisation into the wider context.
- 2.3. A question was raised around the proposed timelines for the pseudonymisation review and how this links to care.data. It was explained that the pseudonymisation review is not working to any externally imposed timelines and will be driven by the time required to evaluate each aspect of the subject. As such its recommendations are not a formal pre-requisite for care.data, which is now planning on taking pilot extracts from GP systems as a discrete piece of work, before proceeding to a second stage based on feedback from the pilot. However, any recommendations made by the pseudonymisation review group would be relayed to the care.data programme by the HSCIC.
- 2.4. A question was raised on whether the review should be extended to cover flows outside the HSCIC. In particular, the potential to link health data to other sets of data was raised. There were mixed views on whether the review should look at the wider system, so it was agreed that initially the review would focus on flows involving the HSCIC. However, the group recognised that the work of the group should be influenced by the broader context and that some of its recommendations may have ramifications beyond HSCIC-related data flows.

**Action – MJ to check how any recommendations from group would fit into wider IG arena**

- 2.5. It was agreed that the group would not explicitly look to revisit the General Practice Extraction Service (GPES) Information Governance principles, but if the group were to produce any recommendations that conflicted with these, further consideration would be needed.
- 2.6. It was agreed that the terms of reference would be updated to include the Nolan principles for public life.
- 2.7. Questions around representatives from the group speaking to the media or sharing papers were also raised and these would be considered in the next draft of the terms of reference.
- 2.8. Terms of reference would include summary of interests of group members and members would be invited to declare any conflicts of interest at each meeting.
- 2.9. It was agreed that minutes would be published, but that comments would not be attributed for specific individuals. A default position was agreed whereby all papers would be published once they were finalised or at a final draft stage. Some papers would be tabled as an initial draft as a stimulus for discussion. Such papers would not be published until they formed an agreed draft. A document classification system and library would assist in the management of this.

**Action – CR to set up document library and set targets for publication of material**

- 2.10. A point was made that the language in all documents needed to reflect what the group was trying to achieve rather than the process by which it would get there. In addition, an agreed standard set of terminology to be used by the entire group was deemed as essential for the group to function. Finally, the complexity of the subject matter was noted along with the need to convey it in a meaningful way to the public.
- 2.11. The group noted that the recommendations it makes should be made to the HSCIC executive management team (EMT) and the recommendations, together with the response from the EMT should be published.
- 2.12. The point was also made that acronyms should be explained in minutes.
- 2.13. Dates for next six meetings would be set with a poll of members taken to ascertain the best data for meeting.

**Action – CR arrange poll of members to determine meeting dates**

**Action – CR update terms of reference for all points listed above and circulate for ratification by the group**

**3. Review initial draft report of review so far**

- 3.1. The group stated that some changes were needed to this report in order to reflect their views before it could be published as a draft. An updated version, incorporating feedback from members, would be discussed at the next meeting of the group.
- 3.2. Initial feedback was given on the paper – members were asked to feed back more detailed comments. A summary of comments voiced at the meeting is below:

- 3.2.1. The paper should not state the pseudonymisation should be irreversible as in certain instances several members of the group stated that this should not be the case.
- 3.2.2. There needs to be greater clarity in the paper on the business problem that pseudonymisation needs to solve, including possible use case.
- 3.2.3. There should be reference to the NHS anonymisation standard.
- 3.2.4. The need for an agreed glossary of standard terms and for language that resonates more widely was again identified.
- 3.2.5. There should be greater reference to the current, “as-is” position on how the HSCIC addresses pseudonymisation.
- 3.2.6. The question of outbound flows from the HSCIC was also very important.
- 3.2.7. The subject of data linkage should be given more consideration.

**Action – group members to feed back comments on draft report of review to date**

#### **4. Next steps and AOB**

- 4.1. Three subgroups will be established to explore specific areas in detail and report back to the steering group, with a group to cover each of the following areas:
  - standards for pseudonymisation including glossary and terminology
  - linkage and data quality
  - other considerations around pseudonymisation at source

**Action – CR to set up sub-groups**

- 4.2. These would report back to subsequent meetings of the group. Further suggestions for subsequent meetings included a focus on current business problems and the need to give the group an overview of how the HSCIC currently applies pseudonymisation.