

## Draft Meeting Minutes

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### Pseudonymisation Steering Group

Meeting 2, Thursday 3<sup>rd</sup> July 2014

The Wesley, 81-103 Euston Road, London, NW1 2EZ

Ratified at 13<sup>th</sup> August 2014 Steering Group meeting

**Present:**

Max Jones(dial in)	Director of Data & Information Services/Pseudo Review Chair	HSCIC
Antony Chuter	Patient Representative	Pain UK, Pain Charities/Research
Harvey Goldstein	Academic Expert on Data Linkage	University College London & University of Bristol
Alan Hassey	Member of Independent Information Governance Oversight Panel	Retired GP
Ian Herbert	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
Hashim Reza	Consultant Psychiatrist and Mental Health Information expert	Oxleas Trust
Chris Roebuck (chair)	Director of Benefits and Utilisation and Review Co-ordinator	HSCIC
Dawn Monaghan (observer)	Group Manager	Information Commissioners' Officer

Kambiz Boomla (observer)		Confidentiality Advisory Group
Matt Spencer	Pseudo Review Project Manager	HSCIC
Wendy Tarbox	Pseudo Review Project Support	HSCIC
Maureen Curran(dial in)	Head of Deployment Support	HSCIC
Ralph Sullivan	HSCIC Primary Care Lead	RCGP
James Wood (dial in)	HSCIC Head of Infrastructure Security	HSCIC
<b>Apologies</b>		
Paul Cundy	Representing British Medical Association (BMA)	General Practitioners Committee and BMA
John Parkinson	User of HSCIC Data	MHRA, Director of CPRD
Wally Gowing	Pseudonymisation Advisor	
Nicholas Oughtibridge	Leading on Code of Practice for Confidentiality	HSCIC
Daniel Ray	Head of NHS Chief Information Officer Network	University Hospital Birmingham

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## 1. Welcome and Introductions

- 1.1. Colleagues were welcomed to the second meeting of the HSCIC's steering group on pseudonymisation. The Chair thanked the group for its contributions over the past weeks
- 1.2. Future scheduled meetings were to be attended in person or via video link
- 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.

## 2. Review of minutes/actions

- 2.1. **3.2.1** – paragraph changed to read ‘ 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’
- 2.2. Action log was reviewed and a number of updates noted. Please refer to action log for details.
- 2.3. It was noted that terms of reference is needed for sub-groups. This needs to cover how we deliver recommendations etc. to the steering group.
- 2.4. The need for a glossary of terms was mentioned for the operation of the Terminology sub-group. The sub-group should look to define terms and feed this to the steering group.
- 2.5. It was further mentioned that a glossary already exists in the Interim Report. It was agreed that Terminology sub-group should use this as a starting point.
- 2.6. It was mentioned that the draft HSCIC Code of Practice and the ISB1523 - Anonymisation Standard for Publishing Health and Social Care Data are relevant and should be made available to the Terminology sub-group.

**Action Point:** To obtain ISB1523 and draft HSCIC Code of Practice and send to Wally Gowing - chair of Terminology sub-group.

## 3. Finalise Terms of Reference

- 3.1. A number of amendments were agreed to the draft terms of reference. Subject to these amendments the group approved these terms of reference. A version with the amendments made will be circulated so the group can approve the wording of the amendments to give final sign off.

- 3.2. A question was raised on whether the Steering Group should feed its recommendations to the HSCIC Board. It was explained that the ToR states that the recommendations should be fed to the HSCIC's Executive Management Team (EMT) and this was deemed appropriate. EMT meets weekly and is responsible for operational decisions, such as the HSCIC's pseudonymisation approach and the board which meets monthly provides approvals for any decisions reached by the EMT.
- 3.3. A general discussion was held regarding Section 2.3 – The Scope of the Steering Group. Specific comments were made regarding the use of HSCIC programmes e.g. care.data when there is no dependency between the Pseudonymisation Review and care.data. Members agreed that references to specific HSCIC programmes be removed and a new paragraph detailing the groups overarching role to the HSCIC. In addition the last sentence should be amended to reference the HSCIC, its data processors or its data controllers and to delete programme specific text.
- 3.4. A question was raised on whether the terms of reference should be extended to cover all HSCIC data and not have a specific reference to care.data. It was agreed that this paragraph should be rewritten.
- 3.5. Paragraph 3.1.6 Political Activity. The group held a lengthy discussion regarding public activity as well as political. The members agreed that the wording of this section should be adjusted to reflect public activity.

**Post Meeting Note:** The Terms of Reference has been amended to include a new paragraph on Public Activity. The ToR will be sent to members for review.

#### 4. Finalise Pseudonymisation Review – Interim Report

- 4.1. Feedback from the review had been received. The Chair explained that the purpose of this report was to set out findings from the pseudonymisation review to date, to support the establishment of the steering group and to present areas for further work by this group.
- 4.2. The group agreed that the document was largely ready to fulfil this purpose and it was important for it go into the public domain promptly, so was happy to sign it off, subject to two group members supplying written comments and points listed below that were raised at the meeting. A version with the amendments made will be circulated so the group can approve the wording of the amendments to give final sign off.
- 4.3. Feedback from the group on the report suggested amendments as follows:
- 4.3.1. Section 2 – Summary of recommendations para iii – Addition of a caveat to read 'except at source' against 'irreversibly'.
- 4.3.2. Paragraph 6.3.2.1 – Debate needs to be informed and measured - The word 'publishing' to be removed
- 4.4. Correct terminology is to be highlighted and reviewed within this group.

#### 5. HSCIC update:

- 5.1. An update was presented to the group which showed that HSCIC was committed to the highest standards of transparency around data sharing. There should be clear access for public/patient on how data are shared.
- 5.2. Partridge Review – referred to all data releases and agreements prior to April 2013.
  - 5.2.1. The HSCIC Board had received a request on nine recommendations and is committed to addressing these and progressing a report (2<sup>nd</sup> July)
  - 5.2.2. Data Register to be published and future reviews of all data received, processed and disseminated by the HSCIC will be published.
- 5.3. Secure Data Labs – An overview was provided.
  - 5.3.1. One of the recommendations from the Partridge review is for the HSCIC to pursue a technical solution to allow access to data without the need to release data out of the HSCIC to external organisations. This is known as Secure Data Labs
  - 5.3.2. Secure data labs are being pursued as a solution that would provide an alternative to data extracts for organisations with appropriate controls and approvals in place. Alongside this the possibility of a public view of Data Labs with completely anonymised data is being considered.
  - 5.3.3. Technical solutions on keeping data within the HSCIC were to be addressed. Secure data labs could and should be implemented.
  - 5.3.4. HSCIC is looking at providing different levels of access to different levels of data.
  - 5.3.5. HSCIC needs to confirm requirements with stakeholders covering Security and Access.
  - 5.3.6. The steering group welcomed the initiative and thought it an important step providing public assurances on how HSCIC manages data.
  - 5.3.7. It was noted that Data Labs could have an effect on how pseudonymisation is considered by the review group.
  - 5.3.8. It was further noted that ‘OpenPseudonymiser’ is based on a model of different levels of access to data.
  - 5.3.9. There is a need for a refined approach on pseudo data labs. The HSCIC is looking at a number of scenarios that would need Secure Data Labs to be in place.
  - 5.3.10. The group is to be kept aware.

## **6. OpenPseudonymiser – Presentation**

A presentation was delivered by Julia Hippisley-Cox

**7. UCL Pseudonymisation – Presentation**

A presentation was delivered by Harvey Goldstein

**8. AOB**

HG advised of upcoming Royal Statisticians Society (RSS) presentation events that may be of interest to members. These are:

Tuesday 7<sup>th</sup> October – RSS presenting at Care.data event

Thursday 13<sup>th</sup> November – RSS presenting on Anonymisation.

MS to send to send web site links of both events for members to consider attending.

**9. Next meeting:** Wednesday 13<sup>th</sup> August 1.00pm to 3.00pm at Skipton House, London.

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