HSCIC Pseudonymisation Review Steering Group

Date:	**Wednesday 3 December 2014**	**Meeting Nr:** **7**
Location:	**Skipton House, London, SE1 6LH**	
Purpose:	**Ratified at January Steering Group**	

Attendees:	Role	Organisation
Anthony Chuter	Patient Representative	
Kambiz Boomla	Observer	Confidentiality Advisory Group
Paul Croft (dial in)	Senior Business Analyst	HSCIC
Harvey Goldstein	Academic expert on Data Linkage	University College London & University of Bristol
Xanthe Hannah (dial in)	Observer	NHS England
Ian Herbert	Primary Health Care IT Specialist Group & 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
John Madsen (dial in)	Head of Productivity & Efficiency	HSCIC
John Parkinson	Observer	Clinical Practice Research Data Link
Hashim Reza	Consultant Psychiatrist	Oxleas NHS Foundation Trust
Jill Reeve (dial in)	Project Support Officer	HSCIC
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
James Wood (dial in)	Head of Infrastructure Security	HSCIC
Apologies		
Paul Cundy	GP	General Practitioners Committee & BMA
Wally Gowing	Pseudonymisation Advisor	Observer
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
Dawn Monaghan	Observer	Information Commissioners' Office
Nicholas Oughtibridge	Lead – Code of Practice for Confidentiality	HSCIC
Richard Pantlin	Social Care Representative	
John Parry	Medical Director	TechUK
Daniel Ray	Head of Chief Information Officer	University Hospital Birmingham

| | Network | |
| Eve Roodhouse | Director care.data | HSCIC |

1.0 Welcome and Introductions

1.1 Colleagues were welcomed to the seventh meeting of the HSCIC Pseudonymisation Review's steering group. The Chair thanked the group for its contributions over the past weeks.

The Chair provided an update on recent changes within HSCIC. Max Jones has now left the organisation. Carl Vincent (Director of Finance & Corporate Services) has taken over the responsibilities, on an interim basis, for the Information & Analytics Directorate within HSCIC and interim responsibility for Data Dissemination programme has passed to Chris Roebuck.

Terry Hill is leading on the backlog of data requests and managing these to approvals stage. The backlog of data requests has now reduced from 600 to 150 and it is hoped that all backlog requests will be approved by the end of January 2015.

The Review's Chair will continue to be Chris Roebuck for the foreseeable future.

The Partridge Review has recently reported and good progress on meeting the review's recommendations has been made but there is still much work to do to meet the recommendations in full.

A consultation around the scope of secure data facilitiy has been completed, with stakeholders from care.data advisory group, and the results will be analysed to inform the next steps.

A programme of audits of recipients of data extracts is being rolled out.

2.0 Review of Minutes/Actions

2.1 The minutes of 5 November Steering group were reviewed with comments raised as follows:

2.1.1 A member stated that the minutes of the last meeting were not sufficiently detailed and clarification was needed on some points. The Chair asked for comments to be sent direct to him.

2.1.2 A member, in referencing **para 2.1.3** commented that what was being said was not clear. The suggestion was this para should be removed.

2.1.3 **Paragraph 3.1.9**, regarding travel expenses for patient representatives, a member stated no answer had been received as yet. It was agreed this is being tracked in the review's action log and an update will be provided.

2.1.4 **Paragraph 3.2.3** – a member queried as to what was being said and suggested it be removed. This was agreed by members.

2.1.5 **Paragraph 3.2.11 -** a query was raised in relation to 'free text' in this para. The paragraph should include the following as this is what was said in the last meeting "*of probabilistic methods (which are best suited for text data such as names addresses and free text)*" and "*required should there be projects which have a legal basis for extracting this type of data*". This was agreed by members.

2.1.6 **Paragraph 3.2.13** – a member asked is Probabilistic in scope for Pseudo @ Source sub-group. The issue is to be raised with the sub-groups chair James Wood regarding the scope of this sub-groups work towards deterministic and probabilistic approaches.

2.1.7 **Paragraph 5.1.2** – a typo in this para, the word 'pack' to be removed.

2.1.8 **Paragraph 5.1.4** – the first two bullets points are shown incorrectly as they should be one point. The para to be amended as agreed.

2.1.9 **Paragraph 6.1.5** – This para should be amended to reflect the fact a member of the steering group disagreed with the comments in this para stating that since care.data has no public plans to extract names & addresses and are currently planning

deterministic linkage the review is highly relevant. Members agreed the para should be amended to reflect the disagreement amongst members.

2.1.10   **Paragraph 6.1.6** – a typo to HSCIC programme name referenced. It should be care.dat**a**.

2.2   Review of Actions

2.2.1   **Action 23** – This is still outstanding. The review project manager has discussed this with John Parry and was advised the Mark Elliott book is delayed to January 2015.The project manger is to contact Mark Elliott for an update.

2.2.2   **Action 30** – The member raising the query on expenses agreed this is now closed.

2.2.3   **Action 31** – The project manager to follow up with JW to establish progress of this action.

2.2.4   **Action 35** – The Chair updated the group on response received from care.data programme. The chair will circulate to the group information on the phases of the Pathfinder programme. Paul Croft – HSCIC commented that 'patient objections' is being included in Pathfinder programme. A steering group member asked if HSCIC is undertaking filtering out of disclosures to third parties The chair responded that this was still being looked as to how to resolve this. Paul Croft commented that work is underway to identify all the assets involved and further commented that Patient Objections would override any S251. However there is no current commitment, yet, when Patient Objections will be implemented. There is a need to work through every single asset for impact of using patient objections.

The chair noted there is a considerable body of views on care.data Pathfinders programme, patient objections and extracts of patient level data. The group should continue discussions offline and to provide comments to him directly.

Action No. 1:   Project Manager to amend November minutes to reflect the above comments and those sent in by members.

Action No. 2:   James Wood – Chair of Pseudo at Source sub-group to detail whether the sub-groups scope includes probabilistic matching.

3.0   Pseudo @ Source Sub-Group Update

3.1   Julia Hippisley-Cox provided an update on the sub-groups progress on behalf of James Wood.

3.1.1   A supplier engagement event is planned for Friday 12 December at TechUK's premises. The event is aimed at understanding the challenges faced by the market place for the use of and implementation of a pseuonymisation at source solution. The objective is to enable the sub-group to understand the detail of any barriers to implementing pseudonymisation at source as a model on the operations of the HSCIC.

3.1.2   Paul Croft updated the group on the proposed workshop involving GPs, Secondary Care, HSCIC and Customers who use data eg researchers. A proforma has been created to ask these stakeholders about the pros, cons and barriers to the different models of pseudonymisation outlined in the review's interim report. The outputs from the workshop and the TechUK event will be used to complete the sub-groups deliverables.

4.0   Data Linkage & Data Quality Sub-group update

4.1   The Chair of the sub-group updated the steering group on activity.

4.2   The CPRD/HES study protocol has been approved by the sub-group and is to be circulated to the steering group at the earliest opportunity. At the present time the studies challenge is obtaining the required approvals to use the data as outlined in the protocol. There is a risk that if approvals are not achieved quickly then then the time available to undertake the protocol will

be lost. Therefore the sub-group need to look at other datasets that are available with existing approvals to undertake either instead of or in addition to using CPRD/HES.

4.3 The sub-group has met a number of times to consider this issue and is tasked with coming up with a short list of datasets that already has approvals.

5.0 Standards and Terminology sub-group update

5.1 The sub-group deputy chair provided an update on the group's deliverables.

    5.1.1 The sub-groups ToR v1.1 has now been approved by the group and therefore presented to the steering group for approval. This was given and agreed that the ToR should be published on the review's website as soon as possible.

    5.1.2 The Context paper v20 has been revised a number of times with sections 1 and 2 being rewritten several times and section 3 contains a lot of duplication. The deputy chair asked for comments from the steering group and stated he hoped the final version will be available for steering group approval in February 2015.

    5.1.3 A member stated the paper should form the basis of 'where' pseudonymisation should not be used. Another member said the paper should reflect the patient's view and that effective linkages of data is needed

Action No 3: **The deputy chair to circulate to the group his comments contained in the paper for review by the group.**

6.0 Royal Statistical Society event feedback

6.1 The paper providing the feedback of the RSS event sent to the group by Wally Gowing but he was not available to present it formally. The feedback was therefore outlined by John Parry who also attended the event.

    6.1.1 The event involving Mark Elliott – University of Manchester and Ross Anderson – University of Cambridge were the speakers giving their views on 'Anonymisation – are the data we release safe?'.

    6.1.2 A key message of the event, for the Review, indicated by both speakers was that anonymisation is difficult to achieve.

    6.1.3 Members commented on the feedback and the findings outlined in the paper from Wally Gowing by exploring a number of areas that the review should consider. These ranged from the need for researchers to use data effectively, pseudo data is possible when it suits the particular purpose, the point at which data is anonymised could facilitate linkage effectively without risk of identifying patients and that increasingly large amounts of data is already collected and often for unknown purposes.

    6.1.4 The wide ranging comments did not materialise in any salient point being captured so members were encouraged by the chair to send any comments on the RSS feedback paper and comments raised to the group.

Action No. 4: **Members to review the RSS feedback paper and provide any comments in writing.**

7.0 Work Plan Review

7.1 A member asked if the election purdah period will affect the reviews work programme. The Chair stated the purdah period often affected strategic decision making at a government level however where decisions affecting business as usual operations these should not be affected.

7.2 The Chair stated the there is still much work to be done and that owners for each line in the work plan should be identified to aid progress on delivery to be measured.

Action No. 5: **The Review's project manager to identify individual leads for each item in the work plan and provide a clear understanding of the position in terms of delivery.**

8.0 AOB

There were no items of any other business raised by members.

9.0   **Next Meeting**

Wednesday 14 January 2015 1300 to 1500 at Tavistock House, London.