## HSCIC Pseudonymisation Review Steering Group

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| **Date:** | **Thursday 8 October 2015** | **Meeting Nr:** | **16** |
| **Location:** | **Tavistock House, Tavistock Square, London and Conference Call**  |
| **Purpose:** | **For Ratification** |

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| **Attendees:** | **Role** | **Organisation** |
| Paul Croft | Senior Business Analyst | HSCIC |
| Antony Chuter  | Patient Representative |  |
| Andy Dickinson | Information Governance SME | HSCIC |
| Harvey Goldstein | Academic expert on Data Linkage | UCL & University of Bristol |
| Ian Herbert | Primary Health Care IT Specialist | BCS |
| Julia Hippisley-Cox (by dial in) | Academic expert on Data Linkage | Nottingham University |
| Chris Roebuck (Chair) | Benefits & Utilisation Director and Review Co-ordinator | HSCIC |
| Matt Spencer | Pseudo Review Project Manager | HSCIC |
| Marc Taylor | Observer | Confidentiality Advisory Group |
| Martin Staples (by dial in) | Observer | NHSE |
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| **Apologies** |  |  |
| Kambiz Boomla | Observer | Confidentiality Advisory Group |
| Xanthe Hannah  | Observer | NHS England |
| Alan Hassey | GP | IIGOP |
| David Ibbotson | Programme Head, Care.data | HSCIC |
| Wally Gowing | Pseudonymisation Advisor | Observer |
| Phil Koczan | GP | RCGP/Health Informatics Group |
| Sean McPhail  |  | Public Health England |
| Dawn Monaghan | Observer | Information Commissioners’ Office |
| Nicholas Oughtibridge | Lead – Code of Practice for Confidentiality | HSCIC |
| John Parry | Medical Director | TechUK |
| Daniel Ray | Head of Chief Information Officer Network | University Hospital Birmingham |
| Hashim Reza | Consultant Psychiatrist | Oxleas NHS Foundation Trust |
| Eve Roodhouse  | Director care.data | HSCIC |
| Tim Williams | Observer | Clinical Practice Research Data Link |
| James Wood  | Head of Infrastructure Security | HSCIC |
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| **1.0** | **Welcome and Introductions** |
| 1.1 | The Chair welcomed everyone to Steering Group’s sixteenth meeting and thanked the group for its contributions over the past weeks.  |
| 1.2 | The Chair requested that the group be updated on HSCIC Patient Objections as follows: |
|  | 1.2.1 | That the Secretary of State (SoS) has directed that the HSCIC puts in place a system to apply patient objections by Jan 2016.There have been a number of policy overrides agreed by the DH.Those objections will apply to patient level data from Jan 2016 where an NHS No. is available on any data disseminations.SoS announced the setting up of an Independent Cyber Security Review to be led by Dame Fiona Caldicot and the CQC.  |
|  | 1.2.2 | A steering group member asked if patients would be informed when their objections are not respected (ie when their objections are overridden).The HSCIC representative providing the update on objections stated that there would be no direct communications to patients but the HSCIC website would outline, through Fair Processing statements, where Objections will be applied or not applied. This would also confirm that S251 applications would respect patient objections in line with the standard conditions of 251 approvals. The steering group member from CAG stated the issue of Objections needs flagging up between CAG and HSCIC and requested that any comms on Objections is made available to CAG for review.The HSCIC Representative also stated that the HSCIC are currently investigating complex cases such as partially consented flows or mixed purpose flows e.g. risk stratification to determine if and how patient objections will be respected.These cases will form part of the Patient Objections Policy which will be approved and owned by the Department of Health. |
| **Action No. 1** | The Review’s Chair asked the Reviews project manager to share any comms material on Objections, when available, with CAG.  |
| **2.0** | **Review of Recommendations v0.5** |
|  | 2.1 | The Review’s Chair asked that members focus in today’s meeting on the Review’s Recommendations as set out in version 0.5 of the Recommendations sent in the previous week. It was noted that a steering group member had sent comments on the recommendations prior to today’s meeting and the group were asked to consider these alongside reviewing the draft version sent out.There followed a short discussion by members on the recommendations document in general. After which it was agreed that specific changes would be applied to version 0.5, within the meeting, and that the resulting consolidated changes would form the basis for the group to agree the Review’s Recommendations.The Steering Group Chair stated it was important to focus on the Recommendations first and that review of the Review’s Final Report should be looked as a basis for providing the context and objectives for the Recommendations. The Review’s Final Report would also need to consolidate any outcomes from remaining sub-group deliverables. And that any individual issues arising, from these remaining deliverables, are to be dealt with on a case by case basis.The Review’s project manager stated the HSCIC team’s current view is that the remaining sub-group deliverables did not materially affect any of the Review’s Recommendations. It was noted however that the review process by sub-group and steering group, of remaining deliverables, will be checked and confirmed back to steering group if any impact materialises. The Review’s Chair noted that the remaining deliverables should be completed alongside the Review’s Final Report.The Chair then asked the steering group to review the draft Recommendations v0.5 and make in line changes within the meeting.  |
| **3.0** | **Review of draft Recommendations v0.5** |
| **Recommendations 1 and 1a** | **Public Confidence****Communicating Benefits of data sharing**The following points were raised by individual members on Recommendation 1and 1a:* Recommendation 1 is not needed as this is what the HSCIC should be doing.
* The Recommendation came from comments raised by external and internal contributors through a number of stakeholder events.
* Another member stated he thought 1 and 1a are needed as HSCIC doesn’t have this elsewhere in the recommendations.
* Another member agreed with the earlier point but stated that without any clear list of data collected by the HSCIC made available to the Review it was difficult to consider if the Recommendation was acceptable.
* Another member stated the recommendation should mention external oversight.
* The member from CAG advised the group that CAG are working on the legal position regarding how it works with HSCIC and that this should be referenced in the Recommendation. On another point the CAG member asked if the Recommendation is talking about pseudonymisation only.
* A HSCIC member in response to above point provided the group with an update on IGARD consultation progress.

More general observations on the Recommendations were raised as follows: * That Recommendation 2 is a technical recommendation and that maybe point made earlier about pseudonymisation as a technique is applicable here.
* That Recommendations 11 and 12 be moved to below 2 as they seem more appropriate there.
* The Review’s Chair stated he thinks the Recommendations should start from a funnel and then drive down to the specifics. So accepts the last point made.
* Recommendation 1a should reflect Risks.
* The Steering group patient representative mentioned that 1a came from his concerns about patients and public awareness of pseudonymisation.
* Another Steering group member suggested Recommendation 2 should be about Sharing of data and that the job of the review is to advise the risk and enable the sharing of data.

*The changes to Recommendations 1 and 1a resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October.* |
| **Recommendation 2** | **Establish Centre of Excellence and Capabilities**The following points were made about Recommendation 2:* That the title be changed to ‘***Establish Centre of Expertise and Capabilities’***
* That it should have Anonymisation added the last sentence.
* That last paragraph is removed and leave it ending at Standard.
* A number of bullets were suggested as replacement for deleted last paragraph to better position what the HSCIC should do.

*The changes to Recommendation 2 resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October.* |
| **Recommendation 3** | **Developments in privacy enhancing technique and technologies*** A member stated he thought the Recommendation was acceptable but there is a need to reduce the words.
* The Steering group agreed that other possible techniques are available but not needed to be reflected in Recommendation. This was agreed by the group.

*The changes to Recommendation 3 resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October.*. |
| **Recommendation 4** | **Dissemination of Data for Purposes with legal basis, including research.**The following points were made about Recommendation 4* If S251 is the only legal basis only if there is no other practical alternative.
* The recommendation is unrelated to the Review’s context and it wasn’t clear what it is saying about pseudonymisation.
* The Review’s Chair agreed it seemed inappropriate to have as a recommendation for a Pseudo review. The suggestion is to delete the recommendation and look to reference it in the Review’s Final Report. This was agreed by the group.

*Recommendation 4 is was deleted and left in as track changes in version 0.6 sent to the group on 9th October.* |
| **Recommendation 5** | **Existing National data flows to HSCIC** The following points were raised about Recommendation 5:* The Review’s Chair stated where the HSCIC is a Data processor then flows would be via S251 and such applications should be reviewed every 5 years.
* A Steering group member stated that there is a need to be clear about Data processor definition as the HSCIC would not be accountable for such data as a data processor.
* A Steering member suggested he wanted to see the addition of ‘particularly for linking data’ to the first sentence.
* Another steering group member didn’t agree to this suggestion.
* The Review’s Chair said the above point’s links to the earlier comment on ‘*no listing of data collections’* and whether we do the activity, in the recommendation, and whether we do it outside of the recommendation.
* The member asking for the addition of the data linkage text stated that if it’s not acceptable then to remove the sentence with ‘identifiable data’.
* Another Steering group member recognises that linkages, as undertaken by the HSCIC, are a major push for identifiable data and therefore understood why the additional text has been proposed.

*The changes to Recommendation 5 resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October*  |
| **Recommendation 6** | **Segregation of patient identifiers from activity data within HSCIC**The Recommendation was accepted with a minor text change applied to the first sentence.*The changes to Recommendation 6 resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October* |
| **Recommendation 7** | **New National data flows**The Recommendation was accepted with a minor text change applied to the last sentence.*The changes to Recommendation 7 resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October* |
| **Recommendation 8** | **Pseudonymisation at Source Proof of Concept**The Recommendation was accepted by the group. |
| **Recommendation 9** | **Local Data Flows**The group agreed this Recommendation be deleted but move ‘HSCIC should advise organisations’ to the Code of Practice*The changes to Recommendation 9 resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October* |
| **Recommendation 10** | **Improving support to privacy of patient data**The group accepted the Recommendation with an additional sentence applied.*The changes to Recommendation 10 resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October* |
| **Recommendation 11**  | **Ensuring use of pseudonymised data is undertaken on a legitimate basis**The Group accepted the recommendation but to delete anonymisation from the Recommendation but need to find a suitable home for it elsewhere.*The changes to Recommendation 11 resulting from the above discussion were applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October* |
| **New Recommendation 12** | **Irreversible Pseudonymisation*** The Review’s Chair discussed creation of a new recommendation to cover Irreversible Pseudonymisation by explaining his thinking about different purposes and different keys being used across different users of data. That data should be collected and disseminated in the least identifiable form dependant on the purposed required.
* A Steering group member raised the issue of disseminations to the different purposes and need for measures to avoid not linking causing re-identification across different purposes.

A form of words setting out the Chairs thinking was drafted in version 0.5 and the group agreed this be reviewed by the whole group to obtain acceptance of the new Recommendation. *New Recommendation 12 resulting from the above discussion was applied to version 0.6 of the Recommendations paper which was sent out for review on 9th October* |
| **4.0** | **AOB**The Review’s Final Report v0.9 has bene sent to the Steering group but it was not possible to review in today’s meeting. Members were therefore asked to review and provide comments by 22nd October.No other items were raised in AOB and the Review’s Chair thanked everyone for attending the meeting and stated he was looking forward to agreeing the Recommendations as soon as possible.  |
| **5.0** | **Next Meeting – A conference call to review the Recommendations and Final Report is to be arranged early November.** |