## HSCIC Pseudonymisation Review Steering Group

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| **Date:** | **Thursday 3 September 2015** | **Meeting Nr:** | **15** |
| **Location:** | **Tavistock House, Tavistock Square, London and Conference Call** | | |
| **Purpose:** | **For Ratification** | | |

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| **Attendees:** | | | **Role** | **Organisation** | |
| Kambiz Boomla | | | Observer | Confidentiality Advisory Group | |
| Antony Chuter | | | Patient Representative |  | |
| Andy Dickinson | | | Information Governance SME | HSCIC | |
| Harvey Goldstein | | | Academic expert on Data Linkage | UCL & University of Bristol | |
| Julia Hippisley-Cox | | | 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 | |
| Martin Staples | | | 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 | |
| Ian Herbert | | | Primary Health Care IT Specialist | BCS | |
| Phil Koczan | | | GP | RCGP/Health Informatics Group | |
| Geraint Lewis | | | Chief Data Officer | NHS England | |
| 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 | |
| Marc Taylor | | | Observer | Confidentiality Advisory Group | |
| 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 fifteenth meeting and thanked the group for its contributions over the past weeks. It was noted the meeting would not be quorate throughout the meeting however the meeting would be progressed in order to review the Review’s draft Recommendations as presented. Decisions and approval of Recommendations would be undertaken at the Group’s next meeting. | | | |
| 1.2 | The Chair outlined the purpose of today’s meeting as follows: | | | |
|  | 1.2.1 | That the Group focuses its attention on the draft Recommendations (v0.2) as presented for review. Some comments, on the draft Recommendations, had been received prior to the meeting and these should also be reviewed along with the formal version presented today.  The draft Recommendations are to be agreed amongst those Steering group members in attendance with actions identified for those Recommendations needed to be agree.  The finalising of draft Recommendations is to be undertaken by remote correspondence with a view to achieving a new draft version for Steering group approval towards the end of September. | | |
|  | 1.2.2 | A steering group member asked about the Sub-groups reports.  The Review’s Chair stated that he was keen that the Review’s Final Report has all of the Recommendations developed and that any sub-group deliverables still in development or review should be aligned with the production, review and approval of the Review’s Final Report.  Another Steering group member asked whether his paper sent to the group on 2nd September, ‘An *Introduction to Recommendations’* could be included in discussions on the Recommendations.  The Review’s Chair asked the member to provide a walkthrough of his paper during today’s meeting.  As there were no further questions the Review’s Chair moved the meeting to the next item on the Agenda. | | |
| **2.0** | **Discussion on overall review and issues identified** | | | |
|  | 2.1 | The Review’s Chair asked for member’s views on how the Review’s work had been undertaken and what challenges there had been.  A Steering group member stated the main challenge had been sub-group deliverables, and still to be presented to Steering group, were still not yet ready. These impacts the Steering group work to agree the Review’s Recommendations and Final Report.  The Review’s Chair agreed that the Review had been impacted by the voluminous deliverables, with some deliverables taking longer than expected to be approved. The Chair stated that any individual issues are to be dealt with on a case by case basis.  Another Steering group member asked about the issue of traceability between the Sub-group’s deliverables and the review’s recommendations.  The Review’s project manager outlined the process to achieve traceability. This involved the evidence from the sub-groups deliverables being referenced the Review’s Assumptions and key findings papers both of which had undergone sub-group and Steering group review over the June, July and August period. The reviews of these papers was conducted through a workshop in June, review at July Steering group followed by remote review and then new versions presented at the Steering groups August meeting. At all times the traceability of evidence through the Assumptions, Key Findings and then the draft Recommendations had been maintained.  The Review’s project manager accepted there they still remained a number of deliverables to review and approve but stated that any evidence form these that is referenced or used in the Review’s Recommendations would be updated once those deliverables had achieved approval status.  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 v0.2. | | |
| **3.0** | **Review of draft Recommendations v0.2** | | | |
| Recommendation 1 | | **Improve awareness of how HSCIC deals with confidential data**  The following points were raised by individual members on Recommendation 1:   * The Recommendation was acceptable but suggested a line be added about communicating technical procedures. * That there should be something on what the public knows or doesn’t know about pseudonymisation. * That Recommendation 1 is the most important recommendation to get right as Professional people will know but the public will not know what pseudonymisation is. * Strengthening is suggested by changing the title wording to have ‘Build’ not ‘Improve’. * Important also to explain importance of the data. There is an issue of being on the defensive in the communications. * Suggestion of another recommendation to clearly link the outcome of the Report to specific datasets. * The above suggestion to be linked to Virtual sharing of data and provide an explanation. * Care.data still overhangs public perception so make clear in the Recommendation that care.data is separate but also explain the safeguards used. * That the HSCIC needs to ‘formally’ act on the Recommendations. * Review’s Chair agreed Recs should apply to HSCIC collections in their entirety and not just care.data. * Agrees there should be a New Rec 2 – *That the HSCIC looks at creating the awareness of the benefits of the data collections*. * The amendment sent prior to the Steering group the suggested changes were acceptable but wording on objections needs refining to clarify differences between Type 1 and Type 2 objections. * Suggested new Recommendation for Patient Objections is not applicable on its own as not in the Review’s scope to define what how PO should work. However reference to PO in other Recommendations should be considered. * The member proposing the new recommendation felt it was important to have as there’s currently no real clarity on process of Patient Objections. * The Review’s Chair agreed clarity on PO has not been helpful. The Review should be concerned with Pseudonymisation of data on Data collections and dissemination and that subject of PO the Review just needs to be aware of the Objections model.   The Review’s Chair summarised the actions for Recommendation 1 as follows:   * The amendment text sent prior to the meeting is accepted in large part. * That an additional line is added about Technical procedures. * To strengthen the recommendation title by changing Improve to Build. | | |
| *New proposed Recommendation 2* | | Respecting patient objections  The members discussed the merits of the proposed new recommendation and after discussion the Review’s Chair stated it should not be accepted but that reference to Patient Objections is made somewhere within the Review’s Recommendations. | | |
| Recommendation 2 | | **Establish Centre of Excellence and Capabilities**  The following points were made about Recommendation 2:   * That a Principle of rolling programme is needed but how this is done needs to be confirmed. * However wouldn’t want to fund another body. A Cost Benefits analysis could be made for such a role. * What was meant by ‘Centre of Excellence’? * The Review’s Chair stated the thinking was for HSCIC to provide the skills, knowledge, organisational capacity to ensure standards, operational capability and legal requirements were understood and implemented. * For such a HSCIC centric recommendation then a reword of the Recommendations tile is needed. * Another member suggested the remit should include Data Linkage strategies. Suggested adding the phrase ‘Would be useful to link to other government bodies’. * That there should be a broad church of people on the body including Patient Reps. * That the recommendation should reference National Standards including those for identifiers e.g. NHS No.   **Action: The Review’s project manager checks with HSCIC Head of Data Quality about standards on identifiers and to include any input to Rec 2**.   * That it should also consider source of data as well in its remit. * The Review’s Chair agrees to make title of Recommendation 2 to make it clearer it’s Internal. * Suggestion from a member was to change it ‘Internal Centre of Excellence’. This was agreed by all members.   The Review’s Chair summarised the action for Recommendation 2 as:   * Draft new Recommendation tile and amend text to reflect points raised. | | |
| Recommendation 3 | | **Developments in privacy enhancing technique and technologies**   * The member who sent a paper on Privacy to the Steering group stated a lot of what his paper covers also covers the content of Recommendation 3. * Another member agreed with Recommendation 3 but suggested the wording needs to be revised. * The Review’s Chair agreed the wording should be more around Security and not Privacy on its own and that it’s about ensuring the techniques are in place.   The Review’s Chair stated the action for Recommendation 3 was:   * Draft amendments to the Recommendation to take account of points raised. | | |
| Recommendation 4 | | **Existing National data flows to HSCIC**  The following points were made about Recommendation 4   * As no formal listing of data coming into HSCIC it’s difficult to consider this Recommendation. Suggest changing to something the HSCIC ‘ intends’ to do * The aim, of the Recommendations, should be to always consider reducing the use of identifiable data. * The Review’s Chair it should be recognised there are instances of use of identifiable data e.g. HES. Challenge is to manage cumulative data from HES and apply P@S. * A Steering group member suggested amending the Rec to say ‘Some identifiable data should continue’ * Another member suggested adding ‘but these flows should be regularly reviewed’. * Another member suggested it should also say for ‘Existing and New Flows’ and that for P@S data that a case should be made. * There should be a comparable review to ensure data doesn’t flow for years with reviewing the data flow is still needed in identifiable form. * The member who provided his *‘Introduction to Recommendations’* paper asked if his proposed new recommendation should be included in Recommendation 4. The Review’s Chair responded that the members’ paper is looking at technical considerations so it should be discussed separately. * A Steering group member stated it is Important to have same procedure (to review use of identifiable data) for both existing and new flows.   The Review’s Chair summarised the points raised:   * + Being transparent in Collections including what legal basis is involved.   + Particular focus for HSC Action directions and not rely on S251 approvals.   + Key is evaluation criteria to be agreed – So assisting decision making particularly for multi data provider scenarios so any use of P@S is clear and unambiguous. * A Steering group member said a statement on costs is needed when looking at different models to be sued. * The Review, and the Recommendation, should say that S251 is a temporary means whereas P@S could be permanent. So onus should be on any need for S251 to be clear. Suggests Rec should focus on S251 not to be used in favour of P@S. * A Steering group member responded that P@S could not be useful on occasions requiring linkages. * The Review’s Chair agreed that there should be a form of a decision tree for P@S were it to be used. For example – Reversible needs to be added to Decision Tree e.g. P@S would affect use of data so benefits of data would be affected. * A member offered the observations that you need to be careful when adding another layer e.g. P@S – So you are not affecting the data in a way that is unhelpful.   The Review’s Chair agreed the further points raised and outlined the following points:   * + That the tabled amendments to Rec 4 for a periodical review are to be considered.   + The Recommendation to still say identifiable data for existing flows can stay subject to other statements/ decision tree.   + That the tabled amendment statement on security & safety should be in Recommendation 5.   + That the suggestion of ‘Irreversible; is not to be used as covered in Rec 11.   The Review’s Chair summarised the main points raised as follows:   * Identifiable data still needed * Periodic reviews should be included. * Decision Points (tree) to be clear about use of identifiable data. | | |
| Recommendation 5 | | **Segregation of patient identifiers from activity within HSCIC**  The following points were raised about Recommendation 5:   * A Steering member felt the recommendation, about branching out of payload and identifiable data, is not needed. * The Review’s Chair stated that the need for handling payload data needed for Linkage (e.g. Mortality > HES) then branching of payload data away from identifiable data is need. * The Steering group member, raising the first point, stated the scenario outlined wouldn’t work – Two datasets with identifiers – Both sets are needed for linkage, * The Review’s Chair suggested Probabilistic matching would overcome this. The branching would be fully audited who has access to what – Issue is those with access both identifiable + payload data. * The Steering group member responded there is a need to argue for secure location for data linkage so it can use identifiable data + payload data. Payload data separated from identifiable data would degrade the quality of linking the datasets. If constraints, on use of payload data, then you destroy the usefulness of the data. * Another steering group member suggested rewording to ‘the system should be designed when identifiable data is needed’. * The Review’ Chair responded that generally identifiable data & payload data should be separated but for linkages (across both) then the controls of this need to be clear and transparent. * A Steering group member stated that no one should have access to both. However the member accepted there may be occasions when both are needed to be viewed. * The Steering group member who suggested the Recommendation is not needed suggested the concern raised is overstated. Unless you cannot see the data then you must allow trusted orgs to look at both data. * The Review’s Chair suggested rewording of Rec 5 to be agreed – Where legal basis is in place then potentially ok. – Add ‘currently’ to Rec 5. * Another member suggested that the Recommendation should also include ‘small space/small set of HSCIC people to view both payload & identifiable data for certain instances of linkage on a limited basis’.   The Review’s Chair stated the Recommendation be reworded taking into account the above points. | | |
| Recommendation 6 | | **New National data flows to HSCIC**  The following points on Recommendation 6 were raised:   * At Steering group member suggested there should be a separate external IG input added to this Rec. as the model of GPES is now missing from current HSCIC approach to external bodies. * Another member confirmed he had responded to the recent IGARD consultations raising concerns about lack of patient representation. * The Steering group member raising the first point asked if a new recommendation on External IG body can be added. * The Review’s Chair stated there are two points to address:   + The members concern with Patient involvement – the Chair will write to IGARD team about this.   + For external IG body – would rather have this addressed through any PIAs and not to include external IG input. * The member raising the point about external IG oversight stated that to improve trust that it is needed. Looking at Rec 1 indicates that HSCIC should look at external input so to say no external IG input, for Rec 6, implies HSCIC is not responding to concerns of external members. * Another member asked what would constitute a new National flow? Another member suggested a new flow from Ministry of Justice data flowing to HSCIC. The member asking the question suggested then that would need external oversight. * The member raining the original point, about need for external IG oversight, asked the Chair how public consultation can be done if there is no Patient Representation on IGARD. The Chair responded that he will raise concerns with IGARD team and that in terms of Rec 6 then it needs to look at expert input not bodies without any knowledge. * General discussion on Patient Rep followed with the Chair closing the discussion by committing to raise with IGARD direct. * A member proposed a further reword for Rec 6 - ‘Subject to IG review, through PIA, and would involve patient groups where required’ this was agreed by all in the meeting. | | |
| Recommendation 7 | | **Pseudonymisation at Source Proof of Concept**   * A Steering group member suggested removing ‘New National’ from the recommendation and that it should read ‘New data’. In addition the criteria proposed for Recommendation 4 should also be used for any new flows in Recommendation 7. * The Review’s Chair suggested that costs of different uses may also impact on any proof of concept proposals.   The Review’s Chair summarised the actions for Recommendation 7 as:     * That the text amendment from New National to New Data be adopted. * That the difference between Rec 4 & 7 is: * 4 – Managed Periodic review cycles. * 7 – The implication of P&S data is to be understood. | | |
| Recommendation 8 | | **Local data flows**   * The group suggested this recommendation be deleted and replaced with a new Recommendation ‘ HSCIC should advise organisations regarding their data flows’ and the proposed amendments for original Recommendation, sent in by a steering group member, be added to Recommendation 9.   The Review’s Chair agreed the suggestion. | | |
| Recommendation 9 | | **Improving support to privacy of patient data**   * A Steering group member suggested that the amendments sent in about HSCIC being “Centre of expertise” should also include advice on encryption tools in Recommendation 9 * The Recommendation should also have anonymised included and to match the text in Recommendation 6 regarding types of data that will be subject to PIA. | | |
| Recommendation 10 | | **Ensuring use of pseudonymised data is undertaken on a legitimate basis**   * A Steering group member stated that use of Pseudonymisation on its own in the Recommendation is limiting. Should be - ‘*Pseudonymised, Anonymised or other treatment, of data, to mitigate the risks involved’*. * Another Steering group member stated this recommendation is an important issue for the. The Recommendation needs to be explicit on what the penalties are if data is used wrongly. * Another Steering group member suggested adding the following to the Recommendation: * ‘including the legal penalties’   The Review’s Chair agreed with the suggestion and asked that the Recommendation be amendment as above. | | |
| Recommendation 11 | | **Irreversible Pseudonymisation**   * Group stated a new Recommendation is needed regarding Pseudonymisation adds security but is not secure on its own. * A Steering group member proposed following text: * ‘The HSCIC should ensure it is secure, NHS wide, but understands that pseudonymisation on its own is insufficient to protect the confidentiality of patient data’. * Another member suggested the addition to the above of: * ‘HSCIC continues to explain the use of anonymising techniques to secure patient data in order to obtain the benefits of the data’. * The group felt the additional statement should be added to the ‘Centre of Excellence’ recommendation.   The member who provided a proposed new Recommendation, sent by email 02/09, gave an outline of its proposals around cumulative encryption.  The Review’s Chair thanked the member for presenting his paper and agreed that his proposed recommendation should be considered as a sub heading to ‘Centre of Excellence‘ in Recommendation 2. | | |
| **4.0** | The Steering group member who provided a proposed ‘Introduction to Recommendations’ paper gave an overview of its contents to the group.  This, the member stated, should be considered for the Review’s Final Report as a way of explaining pseudonymisation and how the Review undertook its review of the topic.  The Review’s Chair thanked the member for providing the proposed text and suggested that it be included in the drafting of the Final Report and that it should be sent to Steering group for review and approval as soon as possible. | | | |
| **5.0** | **AOB**  No items were raised in AOB and the Review’s Chair thanked everyone for attending the meeting and stated he was looking forward to agreeing a set of Recommendations towards the end of September. | | | |
| **6.0** | **Next Meetings – To be arranged towards end of September at Tavistock House, London** | | | |