## HSCIC Pseudonymisation Review Steering Group

|  |  |  |  |
| --- | --- | --- | --- |
| **Date:** | **Thursday 6 August 2015** | **Meeting Nr:** | **14** |
| **Location:** | **Conference Call Only** | | |
| **Purpose:** | **For Information Only** | | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Attendees:** | | | **Role** | **Organisation** | |
| Antony Chuter | | | Patient Representative |  | |
| Andy Dickinson | | | Information Governance SME | HSCIC | |
| Harvey Goldstein | | | Academic expert on Data Linkage | UCL & University of Bristol | |
| Nicholas Oughtibridge | | | Lead – Code of Practice for Confidentiality | HSCIC | |
| Chris Roebuck (Chair) | | | Benefits & Utilisation Director and Review Co-ordinator | HSCIC | |
| Matt Spencer | | | Pseudo Review Project Manager | HSCIC | |
|  | | |  |  | |
| **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 | |
| Julia Hippisley-Cox | | | Academic expert on Data Linkage | Nottingham University | |
| 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 | |
| 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 | |
| Martin Staples | | | Observer | NHSE | |
| Marc Taylor | | | Observer | Confidentiality Advisory Group | |
| Tim Williams | | | Observer | Clinical Practice Research Data Link | |
| James Wood | | | Head of Infrastructure Security | HSCIC | |
|  | | |  |  | |
|  | | |  |  | |
| **1.0** | **Welcome and Introductions** | | | |
| 1.1 | The Chair welcomed everyone to Steering Group’s fourteenth meeting and thanked the group for its contributions over the past weeks. It was noted the meeting was not quorate and would therefore be used to check on progress and to discuss September’s meeting objectives. The 3 September meeting should have an agenda item, early in the meeting, to discuss status of deliverables and any concerns from members.  For today’s meeting notes would be taken but no decisions would be made. | | | |
| 1.2 | The Chair outlined his thoughts on the Review’s progress and next steps. | | | |
|  | 1.2.1 | The Chair stated he was keen that the Review gets to consider Recommendations, from the Review, at the 3 September meeting.  The Chair recapped on some of the discussions in the July meeting that would form the basis of the draft recommendations and felt the meeting was a useful session in which a number of areas of the Review’s work were covered.  There remain several challenges to complete all of the sub-groups’ work but in general the Chair felt there was a real drive, at the July meeting, to start considering potential Recommendations from the Review and if a broad consensus could be reached on these then the remaining task of agreeing some of the material in the detailed papers would be easier.  The HSCIC internal team will draft a set of Recommendations for the steering group to review in September that reflected the discussions in the July meeting. | | |
|  | 1.2.2 | A steering group member asked whether there would be a public consultation on the Review.  The Review’s Chair stated there would not be for the Review but there are a number of other consultations, current and in the future, which will pick this up with their remit particularly in regards to patient data.  The steering group member responded that he was concerned with the long term implications of the Review would not be picked up. The member stated that there would be a public discussion even if there is no formal consultation.  The Chair stated this issue will be driven by the level of consensus of agreement within the steering group. | | |
|  | 1.2.4 | A steering group member outlined his concern that *‘pseudonymisation and impact on patients’* is not being explained in the Review’s work.  The steering group member stated unless you have a particularly detailed interest in the area then you are not going to know what is happening and the safeguards applied.  The Review’s Chair stated that the HSCIC publishes information on organisations to which it has released patient data and the purpose of the use of those data.  Another steering group member suggested that material on protecting, risks, and mitigation steps involved in managing patient data needs to be included in the Review’s work.  The member who raised the concern on impact on patients advised that he thinks one of the Recommendations should be to inform the public of what happens to their data. A suggestion for a poster explaining this in in GP practices should be considered.  The Review’s Chair suggested that this is much wider than just pseudonymisation and should take into account all of the safeguards applied to data and would liaise with the comms team  The steering group member stated the Review’s report should have this included; myth busting communications should be used to reassure the public.  The Chair, responding, felt that such communications should be nuanced including the benefits to health and care of the use of data, the potential for identification from datasets and the safeguards in place to minimise the risk of this happening inappropriately.  The steering group member agreed and further stated if you can quantify the message then it is important to do so.  Another steering group member agreed with the above statements and felt that it should be about the risks of patient data and the purposes for which the data is used for. | | |
| **Action No. 1** | | That the HSCIC participant produces a diagram of flow of data from providers to the HSCIC and onwards, identifying risks and safeguards in place to mitigate them at each stage. | | |
| **Action No. 2** | | That the Review’s project manager liaises with HSCIC comms team around communication of pseudonymisation alongside other safeguards. | | |
| **2.0** | **Review of Key Findings v12** | | | |
|  | 2.1 | The Review’s project manager provided an outline of the main changes in v12 of Key Findings paper from v10. The paper has undergone sub and steering group review, starting with a workshop in June followed by review by correspondence and then reviewed by steering group ain July.  The paper now at v12 is to be used by the steering group to draft recommendations, from the Review, at its September meetings.  The Review’s Chair noted the concern raised by a steering group member that a data quality paper produced by NHS England was being referenced in the one of the review’s findings (finding 37) although the NHS England paper had not been published. The Chair outlined that the findings belonged to the steering group, so there was a need to try to reach consensus on what was incorporated. He stated that the issue of data accuracy, rather than coverage, and its impact on different linkage methods for HSCIC data had not been quantified in the review and this is an area where the report should highlight further work is needed even if not referencing the NHS England report so directly. A draft amendment will be made to finding 37 to reflect this for review by the steering group. | | |
| **3.0** | **Review of Deliverables Status** | | | |
|  | 3.1 | The Review’s project manager provided an update on status of the Review’s deliverables.  There are three deliverables available now for the steering group to review and ratify. These are:   * **ST03 – Report into Pseudonymisation Standards v18** – This has been revised following comments received at the groups May meeting and is presented now for ratification in September. * **ST04 – Legislation relating to Pseudonymisation and Patient Data v07**. This has had several sections amended following the groups May meeting. The main changes are to reflect changes in relationships between HSCIC and Health Research Authority (HRA). The groups’ member from Confidentiality Advisory Group (CAG) outlined in May’s meeting that sections of the HSCA 2012 and Care Act 2014 required an interpretation from HSCIC to allow CAG to understand its relationship and obligations to HSCIC. The Chair of the sub-group has provided a covering note to the steering group explaining all of the changes and stated that these changes have resulted in changes being made to the Review’s Assumptions and Key Findings. * **PS11 – Review of relative security benefits and risks of different pseudo models v0.5**. The author of this deliverable outlined the changes made in v0.5 following comments received at the groups July meeting. The deliverable is therefore presented for steering group to ratify at its September meeting.   There are four other deliverables currently in either development or undergoing review and revision following comments received. It is expected that all four will be made available for the groups September meeting for review and ratification. These are:   * **DLDQ04 – Analysis of Impact of Pseudonymisation on Data Linkage v10**. This deliverable has had several rounds of sub-group review and comments received are currently being reviewed by the internal team. * **PS05 – Report on Pros, Cons and Barriers.** This deliverable due to competing priorities is still in development but resources will be used during August, to complete this for review by the steering group in September. * **PS05 Costs – Report on costs of different Pseudo models.** This deliverable is in development but there are challenges in getting sufficient cost detail to enable a true comparison of costs of the different models to be reflected. For example GP systems costs are an item that is proving difficult to obtain definitive figures that reflect costs for those systems to utilise pseudonymisation techniques. * **PS07 – Report on implications of pseudo @ source on HSCIC DSA, Patient Consent and transparency requirements v0.5**. This deliverable has undergone several rounds of sub-group review. A number of comments have been received on the latest version and these are being revived by HSCIC Information Governance teams as the comments touch on policy issues, for IG, and operational issues on how the HSCIC would manage SARS and S10 requests in a pseudo at source model. | | |
| **6.0** | **AOB**  No items were raised in AOB and the Review’s Chair thanked everyone for attending the August meeting and stated he was looking for a productive meeting in September. | | | |
| **7.0** | **Next Meetings – 3 and 24 September at Tavistock House, London** | | | |