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HSCIC Pseudonymisation Review - Steering Group Terms of Reference

Document Management

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Reviewers

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Matt Spencer	Senior Project Manager	25-07-14	0.4

Approved by

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Pseudonymisation review steering group		25-07-14	0.4

Glossary of Terms

Term / Abbreviation	What it stands for

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1 Purpose

This document describes the Terms of Reference for the HSCIC Pseudonymisation Review Steering Group.

2 The Steering Group's Vision and Context

The Health and Social Care Information Centre (HSCIC) is undertaking a review to determine its approach to pseudonymisation of data it receives, holds and disseminates.

The first stage of this review started in November 2013 and comprised interviews, workshops and correspondence with a number of stakeholders and further discussions with HSCIC business teams. This identified some broad options and criteria against which to assess these options, which are outlined in an interim report available at www.hscic.gov.uk/pseudoreview

A steering group has been established to oversee the next stage of the review, which will produce recommendations in respect of the HSCIC's pseudonymisation approach.

2.1 The Role of the Steering Group

The steering group is an advisory group that will provide recommendations to the HSCIC on its pseudonymisation approach.

The group will agree a set of options in relation to pseudonymisation and a set of criteria for evaluating them against. Where agreement cannot be reached then the divergent views will be noted, together with approximate numbers holding these views.

2.2 The Responsibilities of the Steering Group

The group will be responsible for evaluating the agreed set of options to quantify the advantages and disadvantages of each one and produce recommendations. Where consensus amongst the steering group membership is not achieved, the divergent views will be noted against relevant recommendations, together with approximate numbers holding these views. This position is outlined in Section 4 – Quorum.

In providing these recommendations, the group is expected to take a number of factors into consideration in its evaluation, including but not limited to: technical feasibility, impact on data security, timelines and cost and impact on benefits.

It is envisaged that the steering group will provide recommendations on a specific aspect of pseudonymisation once it has been considered, rather than produce all recommendations together at the end of a process.

The group will be able to request the HSCIC to perform background work to aid it in its evaluation of the different options and assist in the prioritisation of this work. The HSCIC will assess the resource requirement to deliver this background work and decide whether it can deliver it. The Steering Group can invite external experts to its meetings where their skills are pertinent to the particular subject matter being discussed.

The Steering Group (SG) may convene sub-groups to consider specific aspects of pseudonymisation, drawing on a subset of Steering Group members and, where appropriate, external experts. Sub-groups will undertake specific tasks in support of the SG's overall remit and will report back to the SG upon completion of each of these tasks. For further information, see paragraphs 5.1.4 and 5.1.5.

The Steering Group will provide formal recommendations on the following areas:

- The ways in which pseudonymisation could or should feature in relation to current and planned data flows into and out of the HSCIC
- The risks, issues, opportunities and constraints pertaining to pseudonymisation.

The Steering Group will not provide formal recommendations on the following areas, but some of them will be of interest to the group and the group should be mindful of any implications on these areas in making its recommendations:

- The use of pseudonymisation in point to point contexts independent of the HSCIC.
- Assessment of the merits of central data warehouses or models for customers accessing HSCIC data, for example on-site access or delivery of extracts;
- Assessment of consent models, e.g. 'opt in' vs 'opt out';
- Assessment of any Information Governance recommendations that may emerge from the IIGOP
- Any general ethical aspects of using identifiable or de-identified data.

2.3 The Scope of the Steering Group

The Steering Group will provide formal recommendations to the HSCIC Executive Management Team (EMT). The HSCIC EMT will respond to such recommendations.

The Steering Group will have some common membership with the Independent Information Governance Oversight Panel to enable appropriate links to be made. The Steering Group has an overarching role looking at all HSCIC current or future datasets so has no specific links to forums that consider individual programmes of data utilisation, such as the Care.data Advisory Group.

The Steering Group can make recommendations on pseudonymisation of data, current and future, to be received, processed and disseminated by the HSCIC, its data processors or its data controllers in common, where applicable.

2.4 The Membership of the Steering Group

The Steering Group members have been chosen to bring expertise from a range of different perspectives including data suppliers, data users and academic experts. Members do not formally represent a particular constituency and have been selected to ensure that appropriate and balanced advice is provided.

Role on Steering Group	Name	Organisation	Specialism
Chair	Dr Max Jones	HSCIC - Director of Data and Information Services	Chair providing input and Steering Group direction
Member	Chris Carrigan	Public Health England	User of HSCIC Data
Member	Anthony Chuter	Pain UK, Pain Charities/Research	Patient Representative and ex Chair of the RCGP
Member	Dr Paul Cundy	General Practitioners Committee and BMA	Representing BMA in its entirety and GPC is a Sub Committee of BMA
Member	Professor Harvey Goldstein	University College London & University of Bristol	Academic Expert (Data Linkage)
Member	Dr Alan Hassey	HSCIC	HSCIC IG lead and member of Dame Fiona Caldicott's IG panel
Member	Ian Herbert	British Computer Society	Primary Health Care IT Specialist Group and GPES and Independent Advisory Group member
Member	Professor Julia Hippisley-Cox	Nottingham University	Academic Expert on Data Linkage and EMIS National User Group
Member	Dr Phil Koczan	General Practice and Royal College of General Practitioners	Representative of the RCGP and member of the Health Informatics Group
Member	Dr Geraint Lewis	NHS England	Chief Data Officer
Member	John Madsen	HSCIC	Head of Productivity and Efficiency
Member	Dr John Parkinson	MHRA, Director of CPRD	User of HSCIC Data
Member	Daniel Ray	University Hospital Birmingham	Head of NHS CIO Network
Member	Dr Hashim Reza	Oxleas NHS Foundation Trust	Consultant Psychiatrist and Mental Health Information expert
Member	Chris Roebuck	HSCIC	Review Co-ordinator
Member	Eve Roodhouse	HSCIC	Care.data Programme Director

Member	Dr Ralph Sullivan	HSCIC	HSCIC Primary Care Data Director
Member	James Wood	HSCIC	Infrastructure Security Manager
Observers	Natasha Dunkley Dr Kambiz Boomla Marc Taylor	Confidentiality Advisory Group	Provide input on patient confidentiality. N.B. Only one CAG member will attend Steering Group meetings
Observer	Wally Gowing	HSCIC	Pseudonymisation Expert
Observer	Nicholas Oughtibridge	HSCIC	Leading on Code of Practice for Confidentiality
Observer	Dawn Monaghan	Information Commissioners Office	Provide input on confidential data

3 Standards of conduct for Steering Group members

All members are expected to follow the Seven Principles of Public Life (also known as the “Nolan Principles”) ¹ as they apply to the Steering Group.

3.1.1 Exclusions from appointment

Potential members could be excluded from appointment to the Pseudonymisation Review Steering Group for the following reasons:

- i. having within the past five years been convicted of an offence and received a sentence of more than three months’ imprisonment (including suspended sentences), without the option of a fine, unless the conviction was quashed on appeal;*
- ii. having been subject of a bankruptcy order;*
- iii. having had an earlier term of appointment as the Chair, member, director or governor of a health service body terminated in certain circumstances;*
- iv. being under a disqualification order under the Company Directors Disqualification Act 1986;*
- v. having been previously removed from trusteeship of a charity by the court or the Charity Commissioners.*

3.1.2 Requirements for declaration of interests

Every member must complete a full declaration of any interests that could affect, or be perceived to affect, the independence and impartiality of the Steering Group. Members’ interests will be recorded in a Register of Interests by the secretariat which will then be published on the

¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/61402/ministerial-code-may-2010.pdf

HSCIC's website. It is the duty of members to inform the Secretariat if any changes or updates in respect of their interests need to be recorded.

3.1.3 Process for dealing with conflicts of interest

If at any time between meetings a Steering Group member believes there to be a conflict of interest he or she should notify the secretariat, who will update the Steering Group Chair, and the matter should be discussed in advance of the next meeting.

Declarations of interest will be an agenda item at each Steering Group meeting, and any conflicts of interest for that meeting will be recorded in the minutes. The Chair will decide on the appropriate action for each conflict of interest on an individual basis; if the Chair has a conflict then the decision will be taken by a Vice Chair who will be nominated by the Chair and approved by the Steering Group members.

The potential actions are:

- i. The member may be asked to withdraw from the meeting for the duration of the discussion of the agenda item in question; this would only happen in the case of a direct conflict.
- ii. The member may continue to participate in the meeting and contribute to the discussion of the agenda item in question, but would be asked not to participate in the final decision making process.
- iii. The member may continue to contribute as normal if the conflict is judged to be indirect with minimal risk or impact.

The action taken should be recorded in the minutes.

3.1.4 Gifts and hospitality

Members should not accept any gifts, hospitality or benefits as a result of their membership of the Pseudonymisation Review Steering Group or of the recommendations made by the Pseudonymisation Review Steering Group

If members are in any doubt regarding gifts received, including whether to accept them, these should be declared to the Steering Group secretariat.

3.1.5 Public activity

Members are encouraged to promote the general work of the Steering Group in public. Members are also entitled to provide in public their own views around pseudonymisation in a personal capacity. However, members should not engage in public activities that would undermine the work of the group. For example, members would be expected to frame any public activity around whether they are representing the group's views, if they have approval to do so, or their own views.

Any request to represent the views of the Steering Group or provide additional information around discussions of the group beyond the published minutes and Steering Group documents should be agreed with the Chair.

3.1.6 Political activity

Members should not engage in specific political activities on matters directly affecting the business of the Steering Group. In the event of any uncertainty, members should declare their political interests and activities, and these will be kept in the Register of Interests.

3.1.7 Media activity

Any direct media enquiries received by members should be discussed with the Chair. If members are asked to appear at events in the course of their wider work they should make it clear that they are speaking in a personal capacity and not as a member of the Steering Group; if a member is asked to speak specifically on behalf of the Steering Group this must be agreed in advance with the Chair.

4 Quorum

The group will be quorate when the chair and six or more members of the group are present, of whom at least four are external to the HSCIC.

Wherever possible, the steering group should reach a consensus decision for each recommendation.

If a consensus cannot be reached, the divergent views of the group will be noted on a particular recommendation, together with approximate numbers holding these views.

5 Method of Operation

5.1 Meetings

The Steering Group will meet monthly. Extraordinary meetings may be called as necessary. It is envisaged that the steering group will be in operation for at least six months.

The workings of the Steering Group need to be transparent and members should not be constrained in representing their views.

Papers will be submitted one week in advance of Steering Group meetings unless otherwise agreed with the Chair.

All papers presented will be available from a SharePoint site which will be maintained to facilitate the management of documents. There will be three categories of documents:

- i. Draft for initial discussion – documents in this category will be produced by a subset of the group to prompt wider debate and do not necessarily represent the views of the group. Documents will not be made available outside the group at this stage.
- ii. Approved draft – documents in this category will have been discussed by the group but will not represent the final output from the group. Documents at this stage will be published.
- iii. Final document

Once approved by the Steering Group, the minutes of the Steering Group meetings will be published on the HSCIC website. The minutes will provide a full record of discussions that took place, but the comments recorded will not be attributed to individuals.

5.1.1 Standing Agenda

- Minutes from the previous meeting and outstanding actions
- Presentation of papers from sub-groups
- Register of Interests Declarations
- Additional agenda items as pre-agreed by the Chair
- AOB

Ad hoc changes to the agenda to be agreed at each meeting

5.1.2 Inputs

- Minutes from the previous meeting
- Meeting pack:
 - Agenda
 - Actions log
 - Sub-Group papers
 - Date of next meeting
 - Material to support additional agenda items

5.1.3 Outputs

- Minutes - action focused and to record decisions
- Updated action log
- Updated Register of Interest log
- Agreed agenda items for next meeting

5.1.4 Proposed Sub Groups

The Steering Group has initially identified three sub-groups to undertake relevant research and reviews on behalf of the Pseudonymisation Review.

The three sub-groups are:

- standards for pseudonymisation including glossary and terminology
- linkage and data quality
- considerations around pseudonymisation at source

5.1.5 Proposed Sub-Group Scope

Sub-group members will be selected to represent their views and expertise in the respective subject areas of each of the sub-groups.

The Steering Group will consider proposals from sub-groups and, where a majority of members agree, will make appropriate recommendations to the HSCIC EMT

6 Governance

The governance arrangements of the Steering Group and any sub-groups, initiated and approved by the Steering Group, are set out in Appendix 1.

7 Fees and Expenses

Members attending Steering Group meetings can claim reasonable travel and subsistence expenses from the HSCIC, in line with rates and processes set by the HSCIC. Members will be provided with claim forms by the secretariat.

Appendix A – Governance arrangements

