

**Document filename: HSCIC Pseudonymisation Review –  
Standards & Terminology Sub Group ToR v1.0**

<b>Programme</b>	HSCIC Data Pseudonymisation Review	<b>Project</b>	HSCIC Data Pseudonymisation Review
<b>Document Reference</b>			
<b>Project Manager</b>	Matt Spencer	<b>Status</b>	Final
<b>Owner</b>	Chris Roebuck	<b>Version</b>	1.0
<b>Author</b>	Wally Gowing	<b>Version issue date</b>	24/11/2014

# HSCIC Data Pseudonymisation Review - Standards & Terminology Sub-group

---

## Terms of Reference

# Contents

1. Purpose of the Sub-group	3
2. Context of Data Linkage and Data Quality for Pseudonymisation	3
3. Work and associated outputs from the Sub-group	3
4. Membership of the Sub-group	4

## 1. Purpose of the Sub-group

The purpose of the Standards and Terminology Sub-group is to advise the Steering Group on matters relating to standards and terminology.

## 2. Context of Standards and Terminology for Pseudonymisation

The Steering Group's work takes place in the legal and policy setting of the EU and the UK and it needs to be aware of developments in them for protecting identifiable data, such as those raised by the EU Article 29 working group.

Relevant standards in place include the NHS Anonymisation Standard for Publishing Health and Social Care Data ISB 1523, the ICO Anonymisation standard and ISO TS 25237:2008 Pseudonymisation. Under development are ISO 25237:2015 Pseudonymisation and ICO Terminology, Standards and terminology are likely to be modified or developed by changes planned in legislation and the work of the EU Article 29 working group..

These standards contain defined terms and glossaries, which exist alongside similar work done by the Caldicott Reviews et al and being done by the DH.

## 3. The Scope of the Sub-group

The Sub-group will:

- Produce information and reports for the Steering Group on legislation, policy, standards (including the model HSCIC data sharing contract) and terminology that impact on the need for, and operation of, pseudonymisation,
- Scan for potential changes to legislation and policy (e.g. forthcoming regulations, outcome of ASH Regulations consultation, the forthcoming EU data protection regulation) which may impact on standards and terminology relevant to pseudonymisation.
- Review standards relating to de-identification and advise on their relevance to the work of the Steering Group, including identifying any perceived shortfall in the standards and potential requirements for new standards such as an NHS pseudonymisation standard. It will not develop new standards.
- Review developments in definitions, terminology and glossaries and advise on their relevance to the work of the Steering Group, including identifying any perceived shortfall in the terminology and glossaries
- Develop a coherent overview of Standards and Terminology for use within the Review, including a suitable vocabulary and any qualifiers necessary, e.g. 'weak' and 'strong,
- Advise the Steering Group on the possible adoption of glossary/terminologies that should be taken forward by the HSCIC for 'wider health and social care system' usage.
- Liaise with other projects operating in the same or adjacent topic areas to ensure coherence across this aspect of information governance
- Respond to requests/direction from the Steering Group to investigate topics
- The Sub-group will suggest a vocabulary for use by the Steering Group and in the final Steering Group report.

#### **4. Membership of the Sub-group**

The Sub-group shall comprise members of the Steering Group and relevant experts that the Sub-group feels it needs to co-opt to fulfil its remit, especially where overlapping work is already under way, e.g. DH 'standard glossary of terms'. This is subject to the Review's resource constraints. The membership of the Sub-group and the need for co-opted members were confirmed at the first meeting on 3<sup>rd</sup> July 2014

The members of the Sub-group are

- Antony Chuter
- Wally Gowing (Chair)
- Alan Hassey
- Ian Herbert
- Julia Hippisley-Cox
- Sean Kirwan
- Dawn Monaghan (Observer)
- Ralph Sullivan

The Sub-group is supported by Matt Spencer, the Review's Project Manager.

#### **5. Method of Operation of the Sub-group**

The Sub-group will have an initial face-to-face meeting to agree an outline 'programme of work' of tasks to undertake the activities outlined above.

This meeting will be followed by work undertaken as necessary to fit into timetables agreed with the Project Manager for reporting to the Steering Group within its schedule of meetings.

Subsequent meetings are expected to be mainly electronically based, except where significant issues would benefit from resolution through face-to-face meetings.

The HSCIC Pseudonymisation Review SharePoint site should be used as the repository for documents generated in the work.

The modus operandi on reports and decision-making (for recommendations to the Steering Group) will follow the rules set out in the Terms of Reference for the Steering Group.

The sub-group is expected to follow the Steering Group Terms of Reference in regards to Section 3 'Standards of conduct for Steering Group members'.