**Improving outcomes for Looked-After Children**

**John O'Dowd**

**13 June 2014**


**Background**

ScotPHN's needs assessments for looked-after children highlighted the significant health challenges facing this group. The work also highlighted deficiencies in health and social care intelligence around the use of health and social care services, interventions and health and other lifecourse outcomes. The Scottish Directors of Public Health recommended engagement with Government and other stakeholders working in this arena to address these issues.


**Progress**

ISD colleagues have developed a standard minimum dataset which should be used for the annual assessment of looked-after children, in line with previous Scottish Government guidance. This dataset also includes a standardised classification of reasons for the child or young person being looked-after. These developments have been circulated as Government guidance to Boards and local authorities and will drive future local data-collection. Local implementation will require local child public health support. In addition, ISD has been collaborating in an academic project to develop novel data linkage methods to permit meaningful comparisons of the health care and outcomes of looked-after and non looked-after children and young people using nationally held records.  This project is due to report in late 2014. ISD also plans adding LAC fields to additional health data such as the 10 day and 6-8 week child health surveillance system.

Most Health Boards and local authorities already collect bespoke data on their looked-after population. Clarification of the use of CHI as a secondary identifier by the Information Commissioner and CMO has resulted in a CHI field being built into SEEMIS – the predominant education management information system across Scotland. As SEEMIS already holds LAC status data, seeding SEEMIS with CHI data could facilitate local data linkages which will allow a CHI-based register of looked-after children to be developed. This in turn will facilitate local analysis of health status using all available CHI-based health information. In turn, this will permit comparisons between LAC and non-LAC children matched for other possible explanatories such as age, sex and deprivation. Finally, this work will allow multiagency linkage which can shed light on the predictive nature of findings in early life on the lifecourse.

Local data-linkage resources are already in place across Scotland, with centres in Aberdeen, Dundee, Edinburgh and Glasgow. This work is sensitive in terms of public perception of privacy and in terms of reputational risks, particularly to local authority social care partners. Local models exist which will permit locally populated Privacy Advisory Groups to be created in order to oversee the governance of this work. An example of the arrangements is included as appendix 1. The local approach is not intended to compete with the ISD future plans, but to complement them. Such a locally owned approach might therefore address public, organisational and professional concerns raised around privacy, sensitivity and accountability for local data with central linkage activity allowing efficient consistent linkage and comparison.

The implementation of local systems to collect the new minimum datasets for LAC, and plans to make use of existing local data on this group will require local public health leadership combined with a knowledge of local processes, IT systems and actors.

**Recommendations**

SDsPH should endorse this approach to national and local linkage in order to make best use of existing data and inform the improvement agenda.

The SDsPH should provide local leadership on this agenda and identify a named individual to progress this work in each Board.

That local named leads should convene a meeting for shared learning and to agree approaches.

SDsPH are asked to note progress on this initiative through the existing "Group Reports" mechanism.

**APPENDIX 1**

**NHS Greater Glasgow & Clyde – Local Safe Haven**

**Background**

Scottish Government, through the Chief Scientist Office, is supporting the establishment of a local NHS safe haven in each of the 4 larger Boards to support the secondary research uses of clinical data. Currently this type of research is conducted on an ad hoc basis, but the intention of this initiative is to provide a proper governance structure as well as to induce a step change in this activity. It is recognised that only routinely collected NHS data can provide evidence of effectiveness, safety and harm in the heterogeneous patient population that each Board treats.

This is a research initiative but it will provide benefits to the Health Board. In particular, use of routine healthcare information for research purposes will require analysis of and improvement in quality assurance of healthcare data. Such improvements are similar to those needed to support better clinical care. In addition analysis of routinely collected data will provide a cost effective solution to understanding issues that are fundamental to an effective and efficient NHS. However, it must be stressed that use of data for performance management purposes is not envisaged.

**Infrastructure and proposed process**

The infrastructure required has been procured through HI&T and is in place (Appendix A). The intention is not to duplicate NHS clinical datasets but to extract data from clinical systems, when required and at a time of day that is acceptable to the clinical service. However, we will create a core dataset (linked key clinical datasets with SMR, GROS and e-prescribing data) which will be sufficient for many research uses. We are in process of preparing an IRAS submission to gain Ethics approval for the safe haven as a Research Database.

When the use of data is un-consented, use of the data must fall within the REC approval above, and the safe haven will provide access to agreed data views through dumb terminals (after statistical disclosure control). The data itself will not leave the NHS safe haven. If the

use falls out with REC approval, such as for the use of sensitive data, separate REC approval will be required.

When the use of data is consented, as for many clinical trials and studies, the safe haven will release coded (but not identifiable) information. In this case, each trial or study will have its own REC approval and R&D Management approval.

A local Privacy Advisory Committee, chaired by Mary Sweetland, has been established with wide representation from relevant parties. Members are Marian Stewart (Caldicott Guardian), Isobel Brown (Information Governance), Judith Godden (Ethics Scientific Officer), Andy Crawford (Clinical Governance), Duncan Porter (Consultant, Acute), Richard Groden (CHCP), John Ip (LMC), Anne Scoular (Public Health) and Frances Paton (Information Services). The key role of LPAC is to:

- approve guiding principles
- approve processes for bringing data into the safe haven
- agree linkages to new clinical datasets
- approve processes for access to data
- ensure that, when data is linked, privacy risks at the individual patient level are minimised

**Request from Board and Caldicott Guardian**

Before the core linked dataset can be created, extracts from key clinical datasets are required to:

- create data dictionaries
- understand reliability and completeness of data fields
- understand data quality

Access to real data is required for this.

Access to the following datasets is requested:

- SCI store (excluding sensitive data)
- SCI-DC (all sites)
- Cancer Waiting Times
- Rheumatology database
- Athena – Heart Failure database (all sites)
- Parkinson's - Movement disorders database (all sites)

**Creation of the NHS Safe Haven Core Linked Database**

Once this has been done, a core linked database will be created within the NHS safe haven using a NHS GGC population spine. In addition to the datasets described above, the core dataset will contain 5 years data from the following datasets:

- GP Local Enhanced Services data held by the Board (after cleansing by Information Services)
- Scottish Morbidity Records held by the Board, after cleansing by ISD
- Death records held by Board
- Encashed prescriptions (BNF categorised) for 2010 onwards.

The IT infrastructure in the NHS safe haven will enable the core linked dataset holding identifiable information to be stored on one server that can be accessed only by the Safe Haven IT Manager (Marion Flood) and the Safe Haven Developer. An anonymised replica dataset will be held on a separate server, also within the NHS, and it is this dataset that will be used to provide data views on the university side of the safe haven.  The data itself will NOT leave the NHS safe haven.

Appendix A

# Going 'Live'

## NHS Safe Haven

### NHS datasets

| | |
|---|---|
| GP Data | |
| SMR | |
| CHI Seeding | |
| SCI Store | |
| PACS | |
| Other Datasets | |

SQL cluster

Node 1    Node 2

Core Dataset

Linked

Db2

Db3

Database
Anonymised server

Db1

Db2

Db3

Safe Haven Governance

LPAC
decisions

### RCB

Clinical Trials

Research Data

Data
Requests

Application
server

Dumb terminals