SUPPORTING DELIVERY : WORK-STREAM UPDATE
DATA LINKAGE FRAMEWORK BOARD UPDATE

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<th>Issue</th>
<th>For information : the Board is invited to note the update.</th>
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<td>(This standalone paper should be read in conjunction with Paper 3 to provide a full overview of workstream progress and activity).</td>
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<td>NB : An Oral update will support this paper.</td>
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<th>Decisions Required</th>
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<td>Prepared by</td>
<td>DMB Officials Group</td>
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Purpose
1. To provide an update to the Data Management Board regarding progress on (i) the development of SILC, (ii) the retirement of the Data Linkage Framework Programme Board (DLFPB), (iii) the formation of the Scottish Informatics and Linkage Collaboration – Strategic Management Board (SILC-SMB), to which operational oversight of data sharing and linkage in Scotland will transfer.

Background
2. On 29 October 2014, the final meeting of the DLFPB took place, where it was agreed that - as the outgoing Chair - I would provide a progress report to the DMB, outlining handover arrangements and the programme of work SILC will take forward.

3. **Joined Up Data for Better Decisions: A strategy for improving data access and analysis** was published in November 2012 and set out how the strengths and successes of the Scottish Informatics Programme (SHIP) would be expanded beyond the health sector. The Strategy was published alongside the **Guiding Principles for Data Linkage** which were recommend as the basis for all decision making relating to data linkage for research and statistics.

4. The Strategy outlines three main aims:
   i. build on existing successful programmes collaboratively to create a culture where legal, ethical and secure data-linkage is accepted and expected
   ii. minimise the risks to privacy and enhance transparency, by driving up standards in data sharing and linkage procedures
   iii. fully realise the benefits that can be achieved through data linkage to maximise the value of administrative and survey data

5. The Data Linkage Framework, based on the Strategy, comprises four main delivery mechanisms to support achievement of these aims:
   i. the Scottish Informatics and Linkage Centre (SILC)
   ii. the **Guiding Principles for Data Linkage**
   iii. the DMB & DLFPB (now handing across to the SILC-SMB)
   iv. the Public Benefit and Privacy Panel (PBPP)
Achievements
6. The Data Linkage Framework has been delivered, with only the PBPP still under development. A great deal of this work has culminated in the establishment of SILC; a state-of-the-art facility with associated national infrastructure located at No. 9, Edinburgh BioQuarter.

7. At inception, SILC has two main collaborators: the Farr Institute@Scotland and Administrative Data Research Centre - Scotland (ADRC-S). It is anticipated that other collaborators will join as SILC develops. SILC encompasses a number of shared resources which will support collaborators to undertake effective and efficient data linkage. These are:
   i. eDRIS (provided by NSS) - extending within and beyond SILC - provides an advisory service to support researchers and analysts undertaking linkage
   ii. National Records of Scotland (NRS) Indexing Team (funded via ADRC Scotland and the Scottish Government) which will undertake indexing work for both the Farr Institute and ADRC
   iii. Farr IT infrastructure based at both the Universities of Dundee and Edinburgh.

8. A number of Pathfinder projects were funded by the Scottish Government to deliver the aims of the DLF by tackling the challenges that prevent effective and efficient data linkage, helping to develop the current linkage approach and technical delivery capacity for linkage being delivered through SILC. The NRS evaluation of these identifies successes in generating a range of information governance documentation; using analysis reports to inform policy and funding allocations; improved partnerships working and improvements in knowledge and understanding of data sharing and linkage improved across public sector organisations involved; extension of ProcXed data collection and validation tool from Scottish Government.
system allowing other public sector bodies to use this tool; exploring the potential for data linkage in the Health and Environment sectors, reviewing data sources available, evaluating their potential for linkage and tackling uncertainties around the legal and public acceptability of data sharing and linkage through reporting on barriers in each sector; generation of future data linkage work.

9. A number of Scottish Government-funded data linkage projects are underway for research and statistical purposes. It is anticipated these will support the development of evidence-based policy and better public service delivery.

Challenges
10. The Pathfinder Projects Evaluation by NRS also identified a number of challenges including the information governance which can be extremely time consuming to establish and buy-in by senior management buy to ensure progress is made to allow data sharing and linkage to take place; obtaining oversight and ethical approval which can be particularly difficult and time consuming; securing access to data can take up to 18 months which has a huge impact on research, particularly on a 3 year PhD student; care is required in the precise wording of consent as without consideration of data linkage consent can result in greatly limiting what can be done with data; consideration of the Guiding Principles for Data Linkage to ensure consistency and a good practice approach by researchers; ensuring correct resources are available to a project to ensure that progress is made, especially regarding skills.

11. Other challenges have been identified around:
   - communications across data linkage and the wider data landscape (currently being addressed through the SILC Communications and Engagement Group and the DMB),
   - consistency across Safe Researcher Training (a paper will be submitted to the SILC SMB suggesting they act as a formal route for a training)
   - increasing the number of linkage projects being undertaken
   - quickening process

Governance
At the final meeting of the DLFPB, in addition to the handover letter drafted to the Co-chairs of the SILC-SMB, a number of actions were agreed to support the establishment of the SILC-SMB, completeness of the DLFPB and to inform the DMB:
   - identifying lessons learned from data linkage work undertaken by different organisations and how these could be used to make efficiency savings across the process. (To note, having consulted with colleagues in eDRIS, NRS Indexing Team and ICO, Mairead Wood, OCSP, has produced a process flow model for SG-funded data linkage projects to formalise activity, reduce delays and increase efficiency in this area).
   - continuing our cross-sectoral approach, aligning activity to support delivery of the Data Vision.

Prof. Andrew Morris
January 2015