



Data, Statistics and Digital Identity Division

Review: Public Sector Information Governance Framework for Research, and Statistics

Terms of Reference for Working Group

Introduction

1. Scotland is fortunate to have some of the best data in the world. Some data are about people - their characteristics, behaviours and requirements; other data are non-personal - such as data about climate or pollution. Bringing this data together can help address complex social and environmental issues and fill vital evidence gaps.
2. We have robust and proven data hosting and provisioning systems that have delivered significant programmes of cross-cutting research, however innovations in the types of data being analysed and in the methods employed to do this mean that current IG processes are no longer fit for purpose.
3. It is important that systems of hosting and provisioning data have well defined principles and protocols to ensure that data is processed safely, securely, ethically, lawfully and in a manner consistent with public expectations and good science.
4. A key component of this is to have clear processes for Information Governance(IG) of data for research and statistics. Those processes need to be consistent, efficient, and based on informed advice that data controllers and the public can trust. This should build upon the 5 safes model¹ (safe projects, people, settings, data and outputs) to ensure privacy remains at the heart of the way data is used to realise public value. Processes must support secure and carefully controlled access for different types of users from various sectors (health and social care, central and local government, academia, and industry).

Aims and Scope

5. The Working Group is being convened to undertake a programme of change to review, design and deliver a new and fit for purpose Information Governance Framework for data informatics and linkage to support use of all Scottish public sector data for statistics and research in the public interest.
6. The Review will focus on;

¹ <http://blog.ukdataservice.ac.uk/access-to-sensitive-data-for-research-the-5-safes/>

- The use of data for statistics and research in the public interest. This needs to be consistent with the definition for this within UK data protection law and the GDPR.
- This would exclude data sharing for service delivery purposes, although need to explore line between the two and where single structures could serve research and service delivery.
- Governing use of Scottish public sector datasets; not about private/third sector data, although this will include access to public data by private and third sectors, as well as by academics and public sector partners, and the terms of this.
- Wider than data linkage, will include permission processes for access to standalone datasets that contain personal data.

Key Activities

7. The Review will take shape through the following activities;
 - i. To update and refresh Data Governance Policy & Principles (beyond Guiding Principles for Data Linkage)
 - ii. To undertake a literature review and mapping of existing Information Governance processes and structures in Scotland and elsewhere
 - iii. To develop options and recommendation for change of current Information Governance processes for Data Hosting
 - iv. To develop options and recommendation for change of current Information Governance processes for Data Access (including provisioning and approvals)
8. It is proposed that the review will be undertaken in the spirit of Open Government. This means that all meeting papers and draft reports/proposals will be published. There will also be engagement with the public, civil society and privacy groups, as well as with wider public sector partnerships.

Governance

9. A Working Group is being convened to lead this change programme. It will provide a unified direction to the Review. It will meet regularly to develop options, framing issues for consideration, identifying criteria to be used to evaluate proposals. The Working Group will test those processes with key stakeholders and users to ensure they are proving an effective, flexible and proportionate service that complies with current legal frameworks, making recommendations for change.
10. The Working Group will comprise data protection and IG/Caldicott leads from Scottish Government and NHS, along with research service providers and key



data controllers across central and local government, NRS and representation from Chief Scientist for Health, SG.

11. A Steering Group will be convened to provide strategic direction to the Review, ensuring alignment and coherence across the different areas of research and statistics requiring IG protocols and structures. It will also provide a forum through which to escalate issues and provide assurance to relevant delivery programmes. **Through this Steering Group, the DDG will provide accountability and line of sight to Scottish Ministers.**

12. It is proposed that the Steering Group be comprised of members from the Data Delivery Group, plus key data controllers and partners in Scottish Government, academia, service partners and Scottish public bodies.

13. Proposed Membership of Steering Group

- Roger Halliday, Digital Directorate, SG
- Penni Rocks, Head of Digital Health and Social Care, SG
- Ken Macdonald, Head of ICOR (Regions)
- Paul Lowe, National Records of Scotland
- Geoff Huggins, NHS NES Digital Service
- Lorna Ramsay, NHS NSS
- David Crossman, Chief Scientist for Health, SG
- Marian Bain, Public Health Scotland
- Carol Sinclair, Public Health Scotland
- Jill Pell, Director, Institute of Health and Wellbeing, University of Glasgow
- Kevin Collins, University of Edinburgh, Edinburgh City Region Deal
- Chris Dibben, ADR-Scotland Programme Director
- Advocacy Group (to be approached)
- Peter Tolland, Chief Information Officer, North Lanarkshire Council

14. Dependencies and links to other work

- Health and Care Digital Strategy – Domain B
- Public Health Reform – advent of Public Health Scotland
- SILC2 legal entity and commissioning model
- ADR-S Phase 2 Technical Advisory Group and Strategic Impact Programmes
- HDR-UK Innovation Hubs
- NES Digital Platform, NES Digital Service (Geoff Huggins, Dave Robertson)
- Multi-morbidity studies including HDR-UK
- Imaging Project – including commercial access, MRC, HDR-UK
- UNICEF Children's Hub
- Wider SG Data Driven Innovation activity
- UK hosting and provisioning arrangements, incl Digital Econ Act Accreditation

26 March 2019