

Data Delivery Group
24 June 2019
Privacy principles and ethics framework

Purpose of paper

1. To share some of the issues, get a steer how the scope and objectives of such a framework, and help shape how we take forward its development.

Ambition

2. Data is already being used in Scotland to improve people's wellbeing by supporting better decision making by those delivering and delivering public services, and by businesses. This is because we have excellent data, world-class academic power in informatics, public trust in using/handling data, and good links between universities and the NHS in particular. However, we are missing out on significant potential. To start realising that potential, we need to help all stakeholders be clear about permitted uses of data. Having a clear public statement on the key policy questions in this area is important to ensure all people working with data and those whose data are being used know where they stand.

What is currently in place

3. We have some principles underpinning the use of data by people in Scotland. For example our [Identity Management and Privacy Principles](#) and [Data Linkage Guiding Principles](#). These are based upon the 5 safe's principles; more details of which are available at <https://www.ukdataservice.ac.uk/manage-data/legal-ethical/access-control/five-safes>.
4. Scottish Government is currently reviewing arrangements for Information Governance and as part of this are committed to developing a set of data policies and an ethics framework. Scottish Government is also updating the identity elements of the Identity Management and Privacy Principles as part of its development of an approach to Digital Identity.
5. UK Government have set up the [Centre for Data Ethics and Innovation](#), and a few countries around the world have developed data ethics frameworks that are being picked up whose ideas we may be able to draw upon.

Scope

6. We need to agree the scope of the set of policies. The policy questions we will consider are:
 - Which data are used for which purposes and who decides on this?
 - Who will get access to those data and under what conditions? And how we can use research using Scotland's data to promote diversity and inclusion by default. This should include consideration of how to capitalise on expertise of private sector in realising public value
 - How we decide on what to charge for i.e. how should costs of developing the data infrastructure be met. We should consider alternative economic

models and financial arrangements associated with providing access to data to those out-with public sector?

- How does access and permitted use vary by data type? For example, we know from focus groups that some health and financial data are more sensitive than other types.
- What control will citizens have? i.e. Is there a need for opt in or opt out decision on data usage?
- How do we expect to hold and store the data in the future?
- How is the portal to data from multiple sources managed?
- What are the process differences for the use of real-time data vs archival/historical datasets?
- How will we engage the public in this and how their views influence decisions about use of data?

How we take this forward

7. This is an area where Scottish Government should take a lead, though can't achieve objectives without contribution from organisations around Scotland, in particular the members of the Data Delivery Group, as part of our High Level Delivery Plan for data. As with other developments in the data space, we will be developing this using Open Government approaches and principles.
8. Obvious key steps in developing a Scottish data policy and ethics framework are
 - Identifying current approaches in Scotland
 - A short study of approaches across UK and worldwide – is there anything we can use that has been developed elsewhere?
 - Develop options and consult
 - Decide on an approach
 - Develop a communications plan to develop an understanding of the agreed approach.

Questions for the Group?

1. What should the scope for a set of data policies and a data ethics framework be? And what are the issues you think should be included in that document?
2. Are there already exemplars around the world for how this is done that we could draw on or take?
3. What thinking has been done already on these issues in Scotland (beyond what is included in this paper)? And who are the people who we need to involve closely?
4. What are the key components of how we take forward the development of this in Scotland?
5. What engagement would DDG want to take in its development? Would you support a task/finish subgroup to develop the statement of data policies and an data/digital ethics framework?

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