CONSULTATION QUESTIONS

Are you responding *primarily* as a data custodian, data user or data subject? *(We recognise all people are data subjects and many organisations act as data guardians and data users, but please tick only one box)*

Data Custodian ☐

Data User (e.g. researcher) X

Data Subject (e.g. member of the public or group representing citizens) ☐

1. Are there any benefits of data linkage for statistical and research purposes that are not sufficiently described here?

Yes, there are further benefits X   No, the benefits are described fully ☐

If you ticked 'yes', please describe the further benefits of data linkage for statistical and research purposes.

First of all, ESS welcomes this initiative and supports its aims and principles. We think that this framework may be what Scotland needs to ensure that data is produced, gathered and used in a robust way, which makes comparison meaningful.

Benefits 1 and 2 highlight the importance of making use of the data that already exist; however, this framework can potentially be used to identify gaps in the evidence base or in interventions taking place.

Because of the level of synergy between organisations/agencies required for this framework to work, an added benefit could be improved relationships and stronger partnerships.

It will provide a place for those who have robust data but do not have resources to make it publicly available.

If the source of the data is also identified, this could be used to demonstrate the contribution of different sectors. ESS would like to take this comment a bit further: In section 3b. Governance, it is stated that "The Data Linkage Framework" is fully collaborative, cross-sectional, multiagency approach to enabling and facilitating data linkage […]." Yet, the third sector, which is one of the most active sectors holding data, is not mentioned explicitly in the consultation paper. If this framework is meant to hold national data, would not be useful to have links with voluntary organisations too? The Third Sector Research Forum has recently published a paper on "Why involve the third sector in the delivery of health and social care services", which evidences the contribution of the sector and highlights the need for a stronger evidence base. If the voluntary sector had access to a place where

data can be made public that would allow policy and decision makers to have a more realistic picture of how 'policy' is working on the ground. It would also enable agencies to gather data at community level, since third sector organisations are better placed to obtain this data through their strong links to communities and disadvantaged, vulnerable, minority groups.

2. Are there challenges or barriers preventing more effective and efficient data linkages for statistical and research purposes taking place that are not sufficiently described here?

Yes, there are further challenges X   No, the challenges have been identified ☐

If you ticked 'yes', please describe the challenges or barriers.

My comment refers to "Challenge 2: Incomplete data, or data that cannot be linked". When it comes to linking data, it might be easier to link certain types of data, such as hospital admissions, number of intoxications, road accidents, etc., than others such as suicide attempts (some might not make it to health boards or police), sexual abuse, bullying, etc. Some organisations hold this data, which have been collected through questionnaires, interviews, etc., but did not have resources or sophisticated data collection methods to gather it, making it perhaps 'not linkable'. Could the framework support those organisations so that valuable data which is not of enough statistical quality is not lost?

3. Are the guiding principles sufficient and appropriate? Please explain your answer fully and make suggestions for improvement.

Yes, they are sufficient and appropriate X   No, they are not ☐

Please explain your answer fully and make suggestions for improvement.

In general, the guiding principles seem to be sufficient and appropriate. From the perspective of a data provider/user it might be helpful to **have a principle on what the purpose of collecting the data is**, in terms of how it will be used. Data is only as good as the person who collects it. In fact, this issue has been raised by the Scotland Funders' Forum in their **Harmonising Reporting work**, which sets out the principles of good reporting practice. More specifically, **it links to the feedback principle**. This would help those using data to complete reports will understand where the data comes from and why it is appropriate for them to use.

ESS would like to make a small comment in relation to principle 26, by which "all personnel involved in data linkage activities should be properly trained on the data security policies and procedures, and should undertake periodic refresher training". Training should not only comprise of 20 min video tutorial of what good data protection is (what to do and what not to do) and an electronic test with multiple answers to assess knowledge. In ESS's opinion, training should be proportional to the risks around data security.

4a. Are the objectives set out for a Privacy Advisory Service in Section 3c the right ones?

Yes, the objectives are right X   No, they are not ☐

Please explain your answer fully and make suggestions for improvement.

They are appropriate, as long as they apply to all sectors, including the third sector. After all, the Privacy Advisory Service is envisioned as "A Service that can advise on data linkages across sectors as well as within them […]."

4b. Do you wish to be consulted on firmer proposals for a Privacy Advisory service as and when they are developed?

Yes X   No ☐

5a. Are the functions that will be led by the National Data Linkage Centre set out in section 3d the right ones?

Yes, they are the right functions X   No, they are not ☐

Please explain your answer fully and make suggestions for improvement.

Comments

5b. Do you wish to be consulted on firmer proposals for a National Data Linkage Centre as and when they are developed?

Yes X   No ☐