

## 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  | <input checked="" type="checkbox"/> |
| Data User (e.g. researcher)   | <input type="checkbox"/>            |
| Data Subject (e.g. member of the public or group representing citizens) | <input type="checkbox"/>            |

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

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

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

Comments

Aware of the development of the Safe Haven in Greater Glasgow & Clyde and University of Glasgow and discussions have taken place about our future involvement as part of the R&D West Node activity.

These discussions did include IT & Info Gov who were also supportive about exploring this development provided the appropriate safeguards/security are in place .

Developments at a national level are welcomed as this will facilitate local initiatives and provide the services with more rigorous intelligence to drive appropriate service delivery.

### 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  No, the challenges have been identified

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

Comments

The beneficiary of the data linkage is not always the data custodian /

provider so sometimes there will be little incentive for sharing data.

Would there be an overarching body that will “enforce” the sharing of data for overall public interest? Or for commercial gain? (3a point 5)

What bodies would have access to linked datasets e.g. for commercial gain? Please could you provide examples where this may occur?

Do all organisations have the same policies around data release for research purposes and how will this be integrated ?

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

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

Please explain your answer fully and make suggestions for improvement.

Comments

3a Guiding principles points 24 – 28 Security

Require more clarity on the functionality of the “data linkage centre”

Who would have access to the identifiable data and how is access monitored and restricted ?

How will data be extracted, transferred, stored, backed-up ?

How long would it be retained for and how will it be deleted/disposed of?

Who sets the security standards for transfer and storage, agencies involved all differ e.g. not all N3 connections?

In term of security there is no mention of how an information security breach would be managed, responsibilities / liabilities or the traceability of the data.

Clinical trials point 35

The specific circumstances and conditions governing whether or not patients involved in clinical trials can be contacted and by whom, should be clearly set in place in transparent policies

Explicit consent from the patient would have to be gained for additional agencies to contact them as identifiable information would be processed.

The research exemption within the Data Protection Act only applies when:

- the data are not processed to support measures or decisions relating to particular individuals

Direct contact with patients resulting from the sharing/linkage of data would contradict this, explicit consent would always be necessary.

Clinical Trials point 36

Some consent for trials includes participants to have the opportunity to consent to contact by researchers about future trials and therefore this Item should be expanded to include this scenario.

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

Yes, the objectives are right

No, they are not

Please explain your answer fully and make suggestions for improvement.

Comments

In practice how would organisations set up data linkage agreements, would requests for data come directly to organisations or would the Privacy Advisory Service work as an intermediary or would the National Data Linkage Service provide this role.?

Ultimately the data custodians determine the uses of their data, how would that work within the NHS where the data linkage project may require Scotland wide data, would ISD dictate the release of data for linkage purposes?

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

Yes  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

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  No