

Appendix 1. Topic guides

Face-to-face focus groups

Scenario 1 discussion

Now I want you to imagine a scenario. researchers from a University want to collect identifiable data on all children in Wales from their hospital records.

As this data is identifiable the researchers must therefore ask each child's parents for consent to get this data.

This data will be used in a research project that will develop and improve hospital services for children in Wales, this data is not data on child maltreatment.

This data will be transferred from the various records to the researchers by electronic record transfer; that is by sending a file via the internet containing the data.

1. Does anyone have any thoughts about this?
2. Would you decide to give consent depending on what sort of data are going to be collected?

(Prompt: 'Do you feel that data related to some things are easier to give consent to than others?')

3. When data are being sent to researchers from hospital records, do you think that there are more or less security risks when the data are electronic, that is on a computer, or if it's on paper?
4. Sometimes we hear stories in the news about people's data being lost or stolen. Do you think these stories would affect how you felt about researchers collecting and transferring your data even if you were told that the data would be secure?
5. What would be your answer if the researchers were asking your consent for your data to be collected in this way?

Scenario 2 discussion

While the researchers were asking all of the parents in Wales for consent they hit a problem. some of the parents said 'no'.

The researchers would very much like to include all of the children in Wales in the dataset.

So they decide that they would prefer to collect anonymous data, none of the children in the dataset would be identifiable and therefore the researchers would not need to ask the parents' permission to collect this data.

6. Does anyone have any thoughts about this?
7. We have discussed how data can be anonymised. How do you feel about the idea of data being collected without permission needing to be given?' (Prompt: 'Do you think that researchers should ask before obtaining anonymised data, even though they don't have to?')

Scenario 3 discussion

After collecting the anonymous data and doing the research, the researchers now think that they would like to link the data from the hospital records to data in the children's Local Authority records.

Remember that because the data is anonymised the researchers do not need to ask the parents' permission to collect and link this data.

This time however the data will be collected to investigate child maltreatment and how data from the children's hospital records and Local Authority records can be used to improve services for children who are at risk of maltreatment in Wales.

The researchers want to look at different types of data:

- data about cases of child maltreatment that have been confirmed, that is cases where the maltreatment has been investigated by Social Services or the Police and they are sure that it has happened.
- data on 'markers' of child maltreatment, that is things that could make us suspect that there may have been maltreatment but this has not been confirmed e.g. physical signs or injuries that are recorded in hospital records.
- data that may help us predict that child maltreatment might happen in the future e.g. data on domestic violence in the family could be collected because it has been found in the past that violence in a family raises the risk of maltreatment for the child.

8. Does anyone have any thoughts about this?
9. How do you feel about child maltreatment data being collected from different organisations such as from medical records or Local Authority records? Do you feel that it is more acceptable to collect this data from some of these records rather than others?
10. When data that might be considered more sensitive such as data on child maltreatment is being sent to researchers from hospital and Local Authority records, do you think that security is more important when transferring the data or just the same as any other data?
11. How do you feel about researchers collecting data from records about cases of child maltreatment that have been confirmed?
12. How do you feel about researchers collecting data that is what we would call 'markers' of child maltreatment?
13. How do you feel about researchers collecting data on things that may predict that child maltreatment might happen in the future?
14. Are there benefits to this researcher? If so what are they?
15. Do you think researchers having access to child maltreatment data without asking the persons' permission is a good thing or not?
16. If the researchers were asking your consent for your data to be collected in this way, would you say yes or no (or undecided)?

Online focus group

1. How do you feel about child maltreatment data being collected for research from various sources such as from medical records or Local Authority records? Do you feel that it is more acceptable to collect this data from some of these records rather than others?
2. If you know that child maltreatment data may be accessed by researchers; does this affect what data you choose to record?
3. When data that might be considered more sensitive such as data on child maltreatment is being sent to researchers from hospital and Local Authority records, do you think that security is more important when transferring the data or just the same as any other data?
4. Data are often anonymised before being sent to researchers, anonymised data can be sent to researchers without obtaining participant consent. How do you feel about the idea of data being collected without permission needing to be given? Do you think that researchers should ask before obtaining anonymised data, even though they don't have to?
5. Do you think researchers having access to child maltreatment data without asking parents' permission is a good thing or not? Do you think the benefits of research outweigh concerns surrounding security and confidentiality?

