

Exercise

Ca. 20min

Read the three confidentiality statements from (actual) informed consent scripts. For each of them, answer the following questions:

- 1) Could de-identified data be shared through a data repository?
- 2) What are some potential problems of the script? What are some of the strengths?

Which of the three do you like best? Is there anything you would like to change?

Informed Consent 1

All personal information collected in this study including your HIV status will be kept strictly confidential. I will not share the information you provide with anyone who is not part of this research. But it may be shared with fellow researchers and may also be published through meetings or journals in a manner that does not reveal your identity. Before sharing in this manner, the information from you will be combined with that from other research participants. Information which could identify you or anyone related to you will never be released. This also means that names of study participants, including your own will not be included when sharing the data. Recording equipments, recorded information and transcribed data will be kept with identifiers, locked, and only accessible to people that have access keys.

Informed Consent 2

Only [the researcher] will have access to the information on this computer; your recollections will be destroyed once the project has finished.

Informed Consent 3

De-identified data from this study may be shared with the research community at large to advance science and health. We will remove or code any personal information that could identify you before files are shared with other researchers to ensure that, by current scientific standards and known methods, no one will be able to identify you from the information we share. Despite these measures, we cannot guarantee anonymity of your personal data.