

Danish Epidemiology Society: Codex for handling of personal data

The public benefits of epidemiologic and public health research are so persuasive that regulation and legislation should guarantee availability of health data when it is used for purposes such as monitoring disease patterns, better understanding of risk factors for and causes of disease, health care outcomes, and health care organization. Health data should be used to improve health for people without violating their right to privacy. This can be done also for data collected for another purpose without informed consent. This leaves epidemiologists with an obligation to protect privacy, especially for data collected without informed consent. Working with personal data is a privilege that calls for a high degree of data protection- but first principle is to use information to produce information of value for the people. Not to leave that opportunity untouched.

The level of identifiability should always be appropriate to the research goals. Personal identifiers are only needed during data collection and as part of the data cleaning process and should be unlinked as soon as they are no longer needed. If personal identifiers must remain linked to study records, a convincing explanation should be given. The number of individuals authorized with the responsibility for linkage should be limited and all individuals working with data are responsible for ensuring that legal conditions are followed. The principal investigator is responsible for making sure that all members of the team are aware of these rules.

In order to assure confidentiality, identifiable personal data should never be stored on computers outside research establishments and the files containing personal identifiers should be stored separately from the research data, e.g. in locked cabinets or rooms separated from the data used for analysis. Appropriate security measures such as password access and encryption should also be taken to protect data from unauthorized access. Back-up copies must be subject to the same degree of data security and personal data should only be sent from one place to another by secure methods. Epidemiologists should always set up a working standard that minimizes the risk of disclosure of personal information. Larger projects may be better stored and analyzed at Statistics Denmark where logging of data use is recorded routinely.

If approved by data protection agencies, epidemiologists may get access to information collected in health-related registers without personal informed consent. Written informed consent should be obtained when the research involves risks for the individual, but is not necessary if the research poses no threats to the individual. There may be occasions where informed consent is impossible or unethical to obtain e.g. in the use of already existing data, especially when using administrative data in research.

Publication of data should always be in a form where individuals or small groups of individuals cannot be identified and stigmatizing of vulnerable groups should be avoided.

Other relevant homepages:

- [International Epidemiological Association: Good Epidemiological Practice \(GEP\)](#)
- [Persondataloven \(in Danish\)](#)
- [American College of Epidemiology: Ethics guidelines](#)