



FACTSHEET #8

HOW YOUR DATA IS USED IN RESEARCH

WHY DO YOU NEED TO KNOW ABOUT DATA USE IN RESEARCH?

Personal data is vital for many different fields of research and innovation - from advancing medical treatments to developing technologies that improve our lives. But regardless of the potential benefits of their work, researchers in all fields must follow a number of **legal requirements and ethical principles when using our personal data**. This factsheet offers some insights into these rules and principles, and what you can do to ensure they are adhered to.

KEY MESSAGES

- Many types of research require the **processing of personal data** - and researchers must follow several legal regulations when doing this.
- In the EU, many of these are set out in the **General Data Protection Regulation (GDPR)**.
- Among these, researchers are required to: **store personal data securely**; seek your **explicit consent** for its use; and **not use it for any further purposes** without asking again for your consent.
- Researchers should also follow best practices and ethical principles when processing personal data; this is known as **responsible research and innovation**.
- In most research processes, **you have the right to refuse consent** to your personal data being used, or **withdraw it** at any stage of the research process.

VULNERABLE PEOPLE IN RESEARCH PROCESSES

The GDPR lists certain categories of **'sensitive' personal data**, such as data about racial or ethnic origin, political opinions, religious beliefs and sexual orientation, among others. Such data may not be collected - about anyone, not just vulnerable people - unless there is a lawful basis for doing so (as identified in the GDPR) and appropriate safeguards are in place. This provides some level of protection for vulnerable groups in society, such as sexual or religious minorities - but only if researchers adhere to these regulations.



PSEUDONYMOUS AND ANONYMOUS DATA

One way that researchers can reduce risk for data subjects is to make personal data **anonymous** - meaning it cannot be related to a particular person - or **pseudonymous** - meaning it cannot be related to an individual without the use of additional information, which is stored separately. However, this does not completely remove the risk of data misuse. For example, if the data is shared with another researcher, could that second person link it to information that would remove anonymity? PANELFIT's 'Issues and gaps analysis' provides further useful information on this subject (see Section 1.2): bit.ly/3gP2IMT

WHAT YOU CAN DO

- If you are asked to provide personal data for research purposes, you should ask: How is my data being used? Who else will have access to my data? How will my data be stored? When and how can I access the research outputs?
- A researcher should always seek your consent before processing your personal data - and in most cases, you can withdraw this consent at any time should you change your mind.
- If you are not happy with how your data will be used, or with the answers a researcher provides - then you should not give your consent to its use.

FIND OUT MORE

READ: PANELFIT's 'Code of conduct on data protection for responsible research and innovation' is targeted at researchers, but provides useful information for data subjects as well: bit.ly/3gVHiXO