



FACTSHEET #10

HEALTH-RELATED DATA: POSSIBILITIES AND RISKS

WHY DO YOU NEED TO KNOW ABOUT HEALTH-RELATED DATA?

Increasing amounts of **data about our health** - as individuals and as populations - is being collected. This offers **huge potential benefits**: the ability to maximise our healthcare resources, to identify the most efficient treatment for every individual, or to predict future pandemics. But, as with many types of data, **there are likely to be costs** as well. This factsheet looks at the growing field of health-related data: how it can help us and what risks it may pose.

KEY MESSAGES

- **Health-related data** are collected in different ways, for example by hospitals, as digitised records, and on the growing number of health-related apps.
- This offers huge possibilities, from **better coordination of healthcare services** to advanced research into **disease prevention and control**.
- We are also generating **new information about how different activities influence our health**. The concept of health data is expanding to include categories such as 'way of life' and 'level of happiness', or using postcodes to make predictions about our health.
- This offers hope for the future - **but there are also risks**, such as people being denied insurance based on their health data.

VULNERABLE PEOPLE AND HEALTH DATA

Poor health - whether long-term conditions or unexpected illness - makes people vulnerable. In terms of personal data, this raises an issue with informed consent. The General Data Protection Regulation (GDPR; see factsheet #2) requires data controllers (i.e. healthcare professionals) to **seek consent from data subjects** (i.e. patients). But patients may not be able to give this, for example if suffering from dementia; others may give their consent unwillingly, if they think it will help them get treatment. Therefore, **informed consent** (see factsheet #7) may not always be the best lawful basis for processing health data.

THE RISE OF HEALTH APPS



Contact tracing during the Covid-19 pandemic is an example of how we **increasingly share our health data through smartphones apps and mobiles** - also known as mHealth. The benefits are clear: Covid-19 tracing played a significant role in containing the pandemic. But mHealth apps also raise ethical questions: What is being done with the data we submit? Who has access to it? What happens to the millions of people who don't use mHealth apps? What if we start linking drugs to specific apps, such as with so-called 'smart pills'?

WHAT YOU CAN DO

- If you use a health app (e.g. to monitor your heart rate), read the terms and conditions: Who is collecting this data? What are they doing with it?
- Understand the difference between consent related to clinical treatment, and consent for data processing. You do not have to consent to data processing to gain a diagnosis or treatment.
- Your data is yours: you do not have to share it with anyone, including healthcare professionals.
- At the same, some health data deserves to be shared. It might be relevant to your relatives' health, for example, or save someone else's life if it is made available for research.

FIND OUT MORE

READ: The EU-funded INTERVENE project explores how data can advance medical treatment. It uses genomic data (data about our DNA) and health data to develop tools for disease prevention, diagnosis and personalised treatment: (bit.ly/3j5fBOZ). This DataPine article looks at 'Big Data' in healthcare, and some potential benefits (bit.ly/3jdh1a2) and the PANELFIT guide to vulnerable citizens provides more information on health issues and vulnerability (www.panelfit.eu).

WATCH/LISTEN: This PANELFIT monthly chat discusses data protection and health apps in more detail: bit.ly/3d1mVHF