



Data
Saves
Lives

#DataSavesLives

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Health data 101

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To start...

- Health data sharing is a complex area and one that is evolving at an extraordinary pace.
- The process has been transformed by the introduction of new digital ways of storing, exchanging and analysing data.
- More scientific data has been generated in the past five years than in the entire history of mankind!
- It could be used to help prevent illness, improve treatments and access to them, as well as and reduce unnecessary deaths.
- There are already numerous examples of situations in which this has happened.
- This is just the start and the possibilities are infinite.

BUT

To truly harness the power of health data, it needs to be safely stored, shared and used effectively.



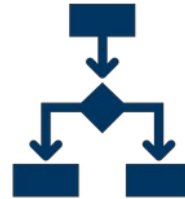
In the last 5 years, more scientific data has been generated than in the entire history of mankind



Explaining how data saves lives can be tough...



Complex topic



Outcome not
always clear



What's in it
for me?



Can appear as 'dry'
facts and figures



Technical language
can be off-putting



What is
the story...



What is health data?

- Health data refers to any data describing a person's health, their healthcare or anything affecting any health issues or diseases they may have.
- It can be collected by healthcare organisations and professionals, about individuals ("personal health data") or populations ("population health data").
- There are many different types of personal health data, including
 - electronic health records (EHR),
 - national databases of prescriptions and lab tests,
 - tracking from mobile apps and wearable smart devices
 - clinical trial databases. Health data is personal and private.

It can contain sensitive information and must be protected





What is 'Big Data'?

- In a healthcare setting, Big Data is used to describe the extensive healthcare databases (like electronic health record systems) or networks of interconnected healthcare databases coming from multiple healthcare organisations.
- These databases contain health data from hundreds, thousands or even millions of individuals.
- Big data can be used to identify specific or unusual patterns of a health condition, to study the impact of different treatments or to discover rare side-effects or long-term health outcomes.



Why is health data so valuable?

- The public health landscape is changing at a rapid pace.
- Populations are growing and people are living longer, but healthcare budgets are not being increased in line with this rising demand.
- There is an urgent need for more effective, less costly and smarter medicines, as well as more holistic care and support for people's individual needs.
- Harnessing the power of health data can help societies to meet these needs and it has already led to some significant advances.



How is health data shared?

Primary use

- Data is originally collected by different organisations, for different purposes, most commonly to support the health and care to individuals.
- These organisations hold patient data in order to ensure that patients continue to receive the best possible care.
- It is generally accepted by most health systems, and by most patients, that an organisation like a hospital will examine its own collection of patient data in order to identify ways that it can improve the quality, timeliness and safety of care that its teams deliver.



How is health data shared?

Secondary use

- However, this data can be collected at a larger population level, for a wider range of learning and improved health care for patients across a wide range of settings.
- This may be within a country or across many countries.
- Individuals have provided their consent for their data to be shared beyond the original purposes for which it was collected, it can be shared via various means.
 - **smart devices**
 - **central computer databases**
 - **from one database to another**
 - **physical form**

How can sharing health data benefit different communities?



Benefits to patients

- Access to personalised data can lead to more efficient and personalised care
- Greater insight into own health, making patients more health literate and offering the potential to adapt lifestyle and interact with healthcare professionals more positively
- Providing data to scientific research speeds up the development of new medical treatments

Benefits to healthcare systems

- Potential to identify at-risk individuals or populations, and speed up diagnosis
- Earlier identification of pathways in disease transmission
- Ability to predict outcomes more accurately and improve the quality and safety of treatments and care

Benefits to healthcare providers

- Ability to design better diagnostic, therapeutic and care pathways and thereby improve patient outcomes and experience
- Insights for improved planning and more efficient use of resources
- Option to participate in more clinical research
- Provides reassurance as recommendations based on more data
- Decreases bureaucracy, where data is made more freely available to base decisions and guidelines on

Benefits to medical research

- Ability to identify people who may benefit from participation in medical research
- Potential to develop new diagnostics and treatments
- Providing data to accelerate regulatory approval of new diagnostics and treatments

Digital Health Tools– CHECK BEFORE YOU CLICK!



- In the past, our health data was largely confined to medical records stored personally or in a family doctor's practice or hospital.
- Today, while some European countries still rely on paper records, digital health devices are part of everyday life.
- Many people wear a smartwatch or fitness tracker. These personal wearable devices can be used to monitor our sleep patterns, track levels of activity or calorie consumption or record pulse rate.
- Patients with certain health conditions may use sensors to monitor vital signs such as blood sugar or heart rate.
- Even if we do not own fitness trackers, many of us download apps to help manage our health.
- We may contribute to online patient groups or take part in online health-based surveys

Often, we make use of digital health tools without giving data protection a second thought.



What are the different types of digital health tools?

Digital health tools use computer platforms, software, apps and sensors to measure different health parameters (e.g. activity levels or sleep patterns) and collect health data about these parameters. They include:

- Smart watches • Fitness trackers
- Mobile health trackers, e.g. to monitor heart rate
- Biosensors to monitor specific health functions, such as blood glucose levels
- Health-based apps
- Online health-based surveys



Can we trust digital health tools?

- It is important to remember that all of these activities generate data about our health and well-being, some of which can be of a sensitive nature.
- Digital health tools increase our 'digital footprint' – the traces of information that record where we've been.
- Some of these tools routinely share our data with third parties, sometimes without our knowledge or adequately informed consent.
- Before signing up to a digital health tool, it is vital to find out what will happen to your personal data and to check whether it will be shared.

Attitudes towards sharing health data

73% of EU citizens want to share health data on the precondition that data is secure and only accessible by authorised parties.

Some 42 % of the respondents fully agree or agree that a lack trust in services providers prevents them from using digital services. The proportion of the respondents who held this view was the highest in Germany (48 %) and the lowest in the Netherlands (38 %).

How can your community feel more confident using digital health tools?



- Hospital and medical records are legally protected in terms of privacy, but this protection does not currently extend to other forms of digital data.
- For example, when a person signs up to a clinical trial, they are specifically told how the data will be used and are asked to sign a consent form.
- In the case of an app, information regarding data protection may be buried deep in a lengthy set of Terms and Conditions that is hard to navigate and even more difficult to understand.

How many of us click the box signifying we have read and agreed to the Terms and Conditions without even glancing at the information?



Key questions to consider

- What personal data will be held?
- Will it be identifiable or anonymised? Remember that even if data is anonymised, it can sometimes be linked up with other information to form a more detailed profile
- Where and how will the data be stored?
- How will the data be protected?
- How will the data be analysed and used?
- Who will have access to the data?
- Will it be shared with third parties?
- Will any of the data be sold to third parties?
- Is there a possibility to opt-out of (i.e. restrict) certain aspects of data sharing?
- In the case of online support groups, who is hosting the site and what is their commitment to data policy? Who will see the information shared?
- Does the company commit to notify users if there is a data breach?
- Can I access my personal data, or ask for it to be deleted or corrected?

How can we identify trustworthy and useful apps?



- As a patient group or individual advocate, you might consider inviting known app developers or industry partners working in your disease area to involve you in the design process of a digital tool.
- This could help ensure that any new app in your disease area is truly useful for affected patients and their families and importantly, that you understand how data will be collected and used.

THANK YOU!

How can you stay connected?



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