EXPLAINING HOW DATA SAVES LIVES

For many people, health data sharing is not an easy concept to grasp. First, they may have no clear understanding of what data sharing is or why it is important. How does it happen and why? Is it a good thing?

Second, health data is inevitably all about numbers and statistics. Few people find this topic particularly stimulating – many people simply switch off when confronted with 'dry' facts and figures. How can we people interested in this topic and encourage them to engage?

This toolkit explains how to breathe life into data and how to illustrate the value and potential of health data sharing.

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

How can we make the topic of health data more accessible?

Many people have probably never really thought about what happens to their health data and how it could be used for the common good. They may find it difficult to appreciate how one person's data could possibly have any impact on public health. **Data Saves Lives** aims to spread the word about the value of *sharing* health data and how powerful this accumulated data can be. It is already transforming healthcare in some areas.

People often find it difficult to relate to statistics. In fact, they can be pretty meaningless unless they are placed in context. In order to encourage people to engage with this topic, we need to bring the subject to life and show how it works in the real world. When statistics are used, it is helpful to illustrate what this means in reality, e.g. 'this new treatment protocol is estimated to have identified x number of at risk patients' or 'x people took part in a recent study – that is equivalent to the population of x'.

Case studies are extremely valuable in this respect as they illustrate the human impact and provide tangible examples of the benefits of sharing health data. They help to capture the imagination about the huge potential of this subject.

Below is an example of a case study and we have included other examples in our toolkit materials.

Data Saving Lives: colon cancer

Challenge: cancer of the colon (bowel) is the second most common cancer with more than 470,000 Europeans being diagnosed every year. Routine screening is available in some countries but around half of those who qualify do not take up the offer. The challenge was to increase uptake of screening

How health data was used: Anonymous patient data from two independent sources (Maccabi Health services in Israel and the UK Health Improvement Network (THIN)) was analysed to develop a new algorithm (computer program) to calculate the risk of people aged over 50 of having colon cancer

The result: The computer program is now available as part of a colorectal cancer screening system in the UK and Israel, allowing clinicians to encourage patients at greater risk of colorectal cancer to come forward for screening.