



INTRODUCING YOUR DATA SAVES LIVES TOOLKIT

Help us to spread the word about how **Data Saves Lives**

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. Incredibly, more scientific data has been generated in the past five years than in the entire history of mankind!

It is no exaggeration to say that this wealth of data has already transformed public health in some areas and has phenomenal potential. 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. To truly harness the power of health data, it needs to be safely stored, shared and used effectively. At **Data Saves Lives**, our mission is to help make this vision a reality.



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The role of patient groups and health advocates

The aim of **Data Saves Lives** is to spread the word about the benefits of responsible health data sharing and to improve health data literacy among patient communities. Patient groups and advocates play a vital role in communicating messages about health data, but levels of knowledge and engagement vary. **Could you help us to spread the word?**

Some of you are already well-informed about the subject and feel confident discussing it with your members or community. Perhaps you are already involved in health data initiatives such as surveys or patient databases. Others may be less familiar with the topic of health data and could have concerns around data privacy and security.

Here, **Data Saves Lives** can support you to start a positive dialogue with your network on the topic of health data sharing – what it is, its benefits, how to address concerns around security and privacy and ways of making health data more accessible and engaging.

Data Saving Lives: cervical cancer

Analysis of the data generated by routine cervical screening of women across Europe revealed the link between HPV and cervical cancer and the need for regular screening. This has the potential to prevent illness and save lives. **Read this and other case studies** at www.datasaveslives.eu

What is Data Saves Lives?

It is a multi-stakeholder initiative led by the **European Patients' Forum (EPF)** and the **European Institute for Innovation through Health Data (i-HD)**. Our aim is to raise wider patient and public awareness about the importance of health data, improve understanding of responsible health data sharing, and establish a trusted environment for dialogue on this issue. We have developed a range of resources to make this possible.

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 and 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 investigate the impact of different treatments or to discover rare side-effects or long-term health outcomes.

Big Data: real-life advances

Published findings derived from Big Data include:

- Validating more than 200 biomarkers (identifying factors) predicting the risk of health disease
- Comparing approximately 8,000 treatment outcomes for leukaemia by age and unearthing a major unmet treatment need
- Analysing more than 700 million records to develop new algorithms to classify cancer risk

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?

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.

However, this data can be aggregated 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. Assuming 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. From a smart device to a central computer database, from one database to another, even in physical form (though digitisation of data has greatly aided its shareability).

How does sharing data improve healthcare?

Sharing data can benefit all sectors of the healthcare community. Patient care is more efficient and co-ordinated, and patients can take a more active role in understanding and managing their own health. Healthcare providers can design better diagnostic and care pathways and use resources more efficiently. In addition, the potential for medical research is enormous, allowing faster development of new treatments.

Data Saving Lives: Alzheimer's Disease

Clinical data was re-used from 1,000 people who had participated in research studies in Europe, to try and develop a test to detect those at risk of developing Alzheimer's Disease. Existing samples and data allowed the research to be completed quickly and at a lower cost, versus setting up a new study, which would have been a lengthy and very expensive process. The initiative was successful and a test has been developed that has the potential to identify those at the earliest stages of the disease, for whom research is likely to reveal the most effective new treatments. **Read this and other case studies at www.datasaveslives.eu**

How can Data Saves Lives support patient groups and health advocates to communicate about health data successfully?

The **Data Saves Lives** website (www.datasaveslives.eu) shares relevant information and examples concerning the use of health data and how to generate easy-to-use materials about the basic concepts of data sharing, the data journey and the safeguards in place.

The website also includes case studies, news updates and a blog with contributions from key individuals involved in the area of responsible health data sharing. It also provides an overview of health data privacy rules and regulations.

At Data Saves Lives, we do not solely rely on our website to achieve our mission of raising awareness of the issues around sharing health data: We also have a strong social media presence; including platforms such as Twitter, Instagram and Facebook.

This introduction forms part of a comprehensive toolkit. It is designed to equip patient groups and health advocates with the information and materials they need to have a positive dialogue with their communities about health data and to potentially launch their own health data initiatives.

Could you develop your own health data project?

The short answer is likely to be 'yes'! This toolkit has been designed with template materials and guidance to help you consider possible next steps. You could even conduct a survey among members on attitudes towards data sharing. There may even be sources of EU funding to help make your project a reality – see the European Commission website for further information (https://ec.europa.eu/info/live-work-travel-eu/health/health-funding_en). Your community could make an important contribution to improving public health.

In summary, why should you support Data Saves Lives?

We exist to spread the word about health data sharing. Now, more than ever, it is a fundamental cornerstone of effective healthcare. Our aim is to equip you with the information you need to have a positive dialogue with your members/community on important subjects around data sharing, including:

- Understanding the basic principles of health data, why it is important and the potential benefits of data-sharing
- Tackling misconceptions about data sharing
- Raising awareness of privacy issues and the need to ensure that data protection is respected
- Making informed choices about health data sharing when participating in clinical research
- Guidelines on using digital health data tools

Encouraging an informed, open discussion about sharing health data is in everyone's best interest. We will all benefit – from individuals to healthcare systems and global populations.

Data Saving Lives: COVID-19

The COVID-19 pandemic has highlighted some of the vital applications for health data sharing. Advances in how we collect and process health data are helping national and global research communities to respond to the virus more effectively. There has been an unprecedented amount of global collaboration, but there is still a need to improve patient literacy about data sharing and the use of data. **Read more at www.datasaveslives.eu**