



Data  
Saves  
Lives



Toolkit



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# 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.



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



## 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](http://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](http://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](http://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](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](http://www.datasaveslives.eu)**



# 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?

<p><b>Benefits to patients</b></p> <ul style="list-style-type: none"> <li>• Access to personalised data can lead to more efficient and personalised care</li> <li>• Greater insight into own health, making patients more health literate and offering the potential to adapt lifestyle and interact with healthcare professionals more positively</li> <li>• Providing data to scientific research speeds up the development of new medical treatments</li> </ul>	<p><b>Benefits to healthcare systems</b></p> <ul style="list-style-type: none"> <li>• Potential to identify at-risk individuals or populations, and speed up diagnosis</li> <li>• Earlier identification of pathways in disease transmission</li> <li>• Ability to predict outcomes more accurately and improve the quality and safety of treatments and care</li> </ul>
<p><b>Benefits to healthcare providers</b></p> <ul style="list-style-type: none"> <li>• Ability to design better diagnostic, therapeutic and care pathways and thereby improve patient outcomes and experience</li> <li>• Insights for improved planning and more efficient use of resources</li> <li>• Option to participate in more clinical research</li> <li>• Provides reassurance as recommendations based on more data</li> <li>• Decreases bureaucracy, where data is made more freely available to base decisions and guidelines on</li> </ul>	<p><b>Benefits to medical research</b></p> <ul style="list-style-type: none"> <li>• Ability to identify people who may benefit from participation in medical research</li> <li>• Potential to develop new diagnostics and treatments</li> <li>• Providing data to accelerate regulatory approval of new diagnostics and treatments</li> </ul>



## 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.



# ENGAGING WITH DIGITAL HEALTH TOOLS – CHECK BEFORE YOU CLICK

As individuals, there are many ways in which personal health data can be collected, even when we are not being actively monitored in a medical setting.

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.

This section of the **Data Saves Lives** toolkit highlights some of the issues associated with the use of digital health tools, providing advice on how to protect sensitive health data. It will support you in answering questions your members may have in this area.

## 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

## The impact of **COVID-19** on medical care

During the COVID-19 pandemic, the number of face-to-face medical consultations declined sharply and increasing numbers of people turned to apps to access support on related topics such as mental health and weight loss. Many healthcare providers also started providing remote consultations, using teleconferencing and digital health tools to help them care for patients.





## Can we trust digital health tools?

Digital health tools have transformed the way people engage with their own health, allowing them to play a greater role in their own well-being. These tools make it far easier to manage some conditions and can alert healthcare professionals to potential problems at an early stage.

However, 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. And 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, for example, 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?

As in so many aspects of life, knowledge is power. Encourage your members to ask a few key questions before signing up to an app or setting up a new fitness tracker. Most online tools will have a Privacy Policy in their Terms and Conditions that sets out how and why data will be used and how it will be protected. It is good practice to check this before proceeding.

### 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?

## What is the role of the GDPR?

The General Data Protection Regulation (GDPR) is a 2018 EU law on data protection and privacy, which includes the transfer of personal data in and outside the EU. This means that the personal data of EU citizens is legally protected, and people must be told how their data will be used, for what purposes and how it will be protected.



It is perhaps not surprising that with concerns about privacy and data breaches hitting the headlines from time to time, some people are hesitant about engaging with digital health tools. Trust can certainly be an issue for some people.

It is all a question of balance. Digital health tools are here to stay. They are accessible, easy to use and most offer benefits in terms of convenience and patient empowerment. To ensure they are used safely, we need to improve patient literacy and equip consumers with the information they need to make informed choices about digital health tools. In many cases, a few simple checks can be sufficient to reduce fears and ensure that consumers engage with these tools in a safe and confident manner.

### **How can we identify trustworthy and useful apps?**

Some patient-led organisations have already reviewed apps for patient communities. For example, MyHealthApps, which was developed in collaboration with patient organisations and launched in 2013, is maintained by PatientView. The website curates hundreds of health apps tried and recommended by patient and health consumer groups worldwide.

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.



# CONVEYING YOUR MESSAGE: COMMUNICATING EFFECTIVELY WITH YOUR COMMUNITY

**When you communicate with your community are you confident that you are conveying your message well? Well-written materials have the power to inform, clear up misconceptions and stimulate action. Poorly targeted items rarely hit the spot and are likely to be ignored, deleted or thrown in the bin.**

We know that many of you feel comfortable developing online or printed materials and have already established a positive dialogue with your members. However, others may be less confident and therefore **Data Saves Lives** has produced this factsheet with general guidance on how to make materials accessible and appropriate for your audience.

## First things first

Before you begin writing, consider the following points:

- Are you absolutely clear **why you are producing this item** and what you want to say? What is the intended outcome, and who is your intended audience? Are you aiming to encourage people to take a specific action?
- Identify your **key messages** and map out a rough plan of sections and what will be included. The content should flow naturally, leading readers through a logical sequence
- What is the most appropriate **format** for your members? An online booklet, factsheet or email? A printed item that can be mailed out? A recorded interview or an animation that can be uploaded to your website? Each of these formats has its own advantages and disadvantages
- How much **detail** do your members need? What is their current level of understanding?



**The most important rule is to ensure that the item you are producing is appropriate for your audience – the right format, the right level of detail and the right content.**





## General language and tone

- Use **everyday language**. Written text does not have to be more complex or formal than the spoken word. Use the same language you would use if you were talking to someone. On the other hand, an occasional colourful expression or unusual turn of phrase can incite interest
- Generally speaking, the simpler the words, the clearer the message
- **Avoid jargon** and explain any technical terms
- If you use an abbreviation (shortening) of a title or organisation, state it in full the first time you use it with the acronym in brackets – e.g. General Data Protection Regulation (GDPR)
- Use the **active voice** with personal pronouns – ‘we’, ‘you’. Speak directly to your audience, e.g. ‘check the Privacy statement on your app’ rather than ‘the privacy policy of your app should be checked’
- Use an **informal, supportive tone** to encourage engagement and involvement, e.g. ‘Together we can ...’, ‘We can help you to ...’  
People do not enjoy being told to do something
- Keep **punctuation** simple
- Always **check spelling and grammar**
- Consider whether terms might be stigmatising, discriminatory or negative about populations or groups

## Layout

- Text is much easier to digest in **short blocks**. Use short paragraphs with 1-2 points in each
- Divide text into sections with **headings and sub-headings** to make it easier to find specific information
- Use **bullet-points** if you have a list of points to make
- Use **call-outs** to highlight key facts. An example is shown below:



**“According to Mental Health Europe, 1 in 4 people will experience a mental health problem in any given year”**



- Vary the format. Use graphics where appropriate to illustrate points
- Avoid using too many colours or different fonts that may distract from the content
- Using a question and answer format can sometimes work well to cover a number of different points
- Avoid long lists of statistics and where you use them, keep them as simple as possible, i.e. ‘almost a third of people’ is more accessible than ‘31% of people’

**Highlighting key information in boxes can help it to stand out**

## Content

- Clearly state what the item you are producing is intended to do. Explain what will be covered in the introduction and then go on to expand
- Do not be tempted to include too much information in one document. You can provide links to more detailed information elsewhere
- Ensure that the level of detail is appropriate for your audience
- Check key facts and if relevant, provide a source reference
- Vary the content if possible. Blend text with graphics, quotes from experts
- Try to end with a **call to action** that is relevant to the content of the item – a prompt to respond in some way or to take a specific action, e.g. ‘Why not check the Terms and Conditions on your fitness tracker?’ or ‘Think about talking to your doctor about taking part in a clinical trial’
- If you are printing items, do not include information that may quickly date, e.g. contact details of specific people within your organisation or details of legislation that is likely to change in the near future. It is better to direct people to your website which can be updated more regularly.

**The section on Explaining how Data Saves Lives includes information on how to bring health data to life.**



# SUPPORTING HEALTH DATA INITIATIVES: SHOULD YOU ENGAGE? A RISK ASSESSMENT TOOL FROM DATA SAVES LIVES

As a patient group or individual advocate, you may occasionally be approached by third parties to support or be involved in a health data initiative or initiatives. This is entirely natural – after all, your members or network can offer valuable ‘real-life’ insights into living with specific diseases and can suggest how improvements could be made in healthcare delivery.

These third parties could be public or private institutions. They could include pharmaceutical companies, healthcare facilities, clinicians, government bodies, academic institutions, commercial technical companies (e.g. app developers) healthcare organisations, research institutions or other patient groups.

Taking part in such initiatives could have a number of advantages.

- It could help to raise your profile or allow you to develop a positive relationship with an influential third party.
- It could increase knowledge about the area you are involved in or facilitate access to support or care for your members.

However, before you sign on the dotted line, it is important to be fully aware of what you are committing to. How will this venture impact your community and your organisation’s reputation? Are there any potential risks or disadvantages?

This tool from **Data Saves Lives** provides a risk assessment framework so that you can assess the pros and cons of any potential project and, if you decide to proceed, allow you to engage in a more confident and informed way.



## What are the opportunities for engaging in health data initiatives?

The possibilities range from simple sharing of information among your members to close involvement in the development of a new digital health tool. Examples include:

- Sharing an online survey with members and encouraging them to participate
- Supporting the development of a new patient registry or greater involvement in an existing one
- Promoting an app among your members and encouraging uptake
- Involving your members in the development or assessment of a new health app
- Sharing or selling data from an existing database of members.

## The value of involving patient communities in digital healthcare design

According to research, patient needs are not always taken into account during the design of digital health tools such as apps and usage is often lower than expected: typical medical or fitness apps have a 90-day retention rate of just 27–30%. To create relevant, usable and effective digital health, it is critical to increase patients' involvement in the design of technological tools.<sup>1</sup>

Before you commit to any project, it is important to ask some **key questions** first to ensure that you have a clear understanding of what is being proposed. These will not all be relevant to each type of initiative but they provide a starting point for discussions.

### The basics

- Exactly what does the project involve – what is its aim and what are the expected outcomes?
- Precisely what are you being asked to do? Has it been set out in detail and do you understand what is being asked of you?
- Is there any financial remuneration and if so, is this at an appropriate level? Fair market value (FMV) may differ from country to country. How and when will payment be made?
- How much of your time will the project involve? Do you have the capacity to devote this time to the exercise? Will you need to be involved personally?
- Who will be your point of contact?
- Will you be updated as the project progresses?
- What is the timescale?
- How will your organisation benefit from involvement? Will the project provide relevant data and will this be shared with you? Will it empower your members in any way or lead to the development of a tool that could be beneficial to them?

### How will this exercise reflect on you and your organisation?

- Will your involvement be made public? How will this be done?
- Will this have a positive impact on your profile, for example by positioning your organisation as forward-thinking or innovative?
- Could there be any downsides, e.g. perceived influence from third parties that could affect independence/credibility?
- Will you have the option to see any materials relating to the project you are involved in before they are published?
- Who will have the copyright to the material?

*“Many companies have developed new ways to incorporate patient insights and to collaborate with patients and patient organisations in a transparent and ethical way. This has led to better trials, better engagement, better communication throughout the entire life cycle of medicines – and ultimately better patient outcomes”*

**European Federation of Pharmaceutical Industries and Associations<sup>2</sup>**

### Safeguarding privacy

- If your members are being asked to contribute data, how will this data be used? Will it be shared with third parties?
- Will the data be anonymised?
- Will you have access to the full set of data?
- If you are considering sharing or selling member data, has this been made clear to members in your Privacy Policy? Could this impact their trust in your organisation?

## Before you go ahead

If you decide to proceed with a health data initiative with a third party, there are a few final points to consider.

- How much information do you need to provide to your members?
- Do you need to make a more public declaration? For example, if you are working with a pharmaceutical company it is important to be transparent about this, particularly if you are receiving payment of any kind.

**If the third party you are engaging with is not able to answer your questions fully or you feel uncomfortable with any aspect that is being asked of you, it may be wiser not to proceed or to take some time to consider your options. Do not feel pressured into taking part. The potential benefits of involvement in a joint health data initiative are significant, but there are certainly downsides to consider.**

Below is a table which you can use to record your thoughts on a project and keep them for future reference.

<b>Project details</b>	
<b>Level of confidence on scale of 1–5*</b>	
<b>Comments/further action needed</b>	
<b>Additional comments/final decision</b>	
<p><b>*Confidence level</b></p> <ol style="list-style-type: none"> <li>1. Not satisfied with answers to questions/insufficient information to make an informed decision</li> <li>2. Some areas of interest but significant additional information/reassurance required</li> <li>3. Promising proposal but additional information/clarification required</li> <li>4. Largely satisfied with proposal, clarification on final points appreciated</li> <li>5. Fully satisfied with proposal: willing to proceed</li> </ol>	

### References

1. Patient Engagement and the Design of Digital Health - Birnbaum - 2015 - Academic Emergency Medicine - Wiley Online Library
2. working-together-with-patient-groups-23102017.pdf (efpia.eu)



# DATA SAVES LIVES TEMPLATE WEBINAR AGENDA AN 'INTRODUCTION TO HEALTH DATA'

One of the ways the team at Data Saves Lives has found success in raising awareness of and communicating about health data issues is by holding public webinars with its communities and their wider networks.

If you are a patient group that is interested in running your own online webinar with a panel to provide an introduction to health data for your members, you may find this 90-minute agenda template a helpful starting point for your plans.

The European Patients' Forum (EPF) and the European Institute for Innovation through Health Data (i~HD), which have been leading the Data Saves Lives initiative to date, are both useful groups to contact for guidance on potential expert speakers to feature in your webinar. You can access previous webinar recordings from Data Saves Lives via our YouTube channel.

## Webinar objectives

Following the webinar/workshop, attendees should be able to:

- **Better understand the benefits** of health data sharing for patients, healthcare systems, healthcare providers and medical research
- **Better understand the principles** behind data and privacy protection and how data protection measures should be implemented for health data sharing
- **Be more confident** in making informed choices about the use of their personal information





Timing	Agenda	Lead
5 mins	<b>Introduction and housekeeping</b>	Host
10 mins	<b>What is electronic health data? And who benefits from health data sharing and how?</b>	Expert speaker
10 mins	<b>What data protection measures are needed to protect the privacy of individuals when sharing health data?</b>	Data privacy expert speaker
10 mins	<b>Keynote presentation on a patient organisation-led health data project, focusing on benefits of their health data sharing initiative, how they implemented data protection measures and how they overcame any barriers around these</b>	Patient organisation representative
50 mins	<b>Open forum discussion</b> <i>Example facilitator questions (to be posed to the expert panel or to the audience):</i> <ul style="list-style-type: none"><li>• Are there any other benefits to health data sharing that have not been discussed so far on this webinar? Or are there benefits which you think need to be discussed in greater depth?</li><li>• How do you think patient groups can best communicate the benefits of health data sharing?</li><li>• Implementing data security measures can be seen as cumbersome, very technical and requiring a lot of time. How would you respond to this?</li><li>• Are there any existing practical resources that would help to overcome perceived challenges of implementing required data protection measures?</li></ul>	Host / independent facilitator
5 mins	<b>Round up</b>	Host



# DATA SAVES LIVES TEMPLATE SURVEY TO UNDERSTAND PATIENT AND CARER CONFIDENCE IN HEALTH DATA-SHARING

As a starting point to help you better understand the knowledge and beliefs around health data sharing of your community, **Data Saves Lives** has developed this easily adaptable survey template that you can tailor to suit your needs.

Online survey platforms, such as SurveyMonkey® and Google Forms®, provide a secure and accessible way of surveying your members or network and are intuitive to set up. These platforms can be accessed by non-paying account holders and allow users to upload and share surveys, with a limit of 10 free questions on SurveyMonkey®. They also both provide supplementary analytics and statistics of the results after the survey has been completed and are an extremely useful tool for patient groups or individuals with limited resources.

We recommend if you share a survey like this with your members or network, that you include a description of what electronic health data is as an introduction, to provide context. You can use the description from the introductory section to this toolkit.

*Example survey questions begin on the next page...*



## Example survey questions

### 1. On a scale from 1–5, to what extent do you agree with the statements below? (1 = completely disagree, 3 = neither disagree nor agree, 5 = completely agree)

- I feel comfortable sharing my health data if I know it is contributing towards wider-societal benefit
- I feel confident that there are safeguards in place that will protect my health data and ensure that it is not exploited for commercial gain
- I understand what happens to my health data once it has been shared and who controls it
- I feel confident that by sharing my health data, my information will make a positive impact in the field of medical research and clinical trials
- By donating my health data, I feel confident that my privacy and anonymity (should I choose to remain anonymous) is protected
- I understand what my given consent implies when I agree to provide health data and the 'limitations' of this consent, such as in instances where I should choose to withdraw it
- I believe that by donating my health data, I may suffer adverse consequences as a result e.g. it could affect my health insurance, or my employment options
- I fully trust that healthcare regulatory bodies and corporations will use my data to benefit society at large
- I am concerned about sharing my personal health data (and those separate from my condition(s) – such as age, ethnicity & sexual orientation) in case it is made publicly accessible

### 2. Which individuals or organisations do you feel most comfortable sharing your health data with? **Tick all that apply**

- |                                             |                                                 |
|---------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> My healthcare team | <input type="checkbox"/> Mobile phone apps      |
| <input type="checkbox"/> Hospitals          | <input type="checkbox"/> Digital health tools   |
| <input type="checkbox"/> Universities       | <input type="checkbox"/> Online forums          |
| <input type="checkbox"/> Drug companies     | <input type="checkbox"/> Social media platforms |
| <input type="checkbox"/> Charities          | <input type="checkbox"/> Medical devices        |
| <input type="checkbox"/> Patient groups     | <input type="checkbox"/> Other [Open text]      |



**3. Which individuals or organisations do you feel least comfortable sharing your health data with? Tick all that apply**

- |                                             |                                                 |
|---------------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> My healthcare team | <input type="checkbox"/> Mobile phone apps      |
| <input type="checkbox"/> Hospitals          | <input type="checkbox"/> Digital health tools   |
| <input type="checkbox"/> Universities       | <input type="checkbox"/> Online forums          |
| <input type="checkbox"/> Drug companies     | <input type="checkbox"/> Social media platforms |
| <input type="checkbox"/> Charities          | <input type="checkbox"/> Medical devices        |
| <input type="checkbox"/> Patient groups     | <input type="checkbox"/> Other [Open text]      |

**4. Please explain your responses to questions 3 & 4. [Open text]**

**5. What concerns might you have regarding your health data use? [Open text]**

**6. In your opinion, what could patient groups and data collectors do to address these concerns and increase your trust in health data-sharing initiatives? [Open text]**

**7. If you are interested in learning more about health data, which methods of communication would you find most helpful from us? Tick all that apply**

- |                                                                     |                                                                  |
|---------------------------------------------------------------------|------------------------------------------------------------------|
| <input type="checkbox"/> An online webinar                          | <input type="checkbox"/> More information on our website         |
| <input type="checkbox"/> A discussion session at our annual meeting | <input type="checkbox"/> Regular updates on research initiatives |
| <input type="checkbox"/> A factsheet                                |                                                                  |

**8. Please confirm if you are:**

- |                                    |                                            |
|------------------------------------|--------------------------------------------|
| <input type="checkbox"/> A patient | <input type="checkbox"/> Other [Open text] |
| <input type="checkbox"/> A carer   | <input type="checkbox"/> Prefer not to say |



# 10 THINGS YOU MAY NOT KNOW ABOUT HEALTH DATA

## *Fact sheet to share with your networks*

### **1. The first electronic health record (EHR) was created in 1969.<sup>1</sup>**

Before the worldwide phenomenon that is computer technology became widely known and used, Dr Lawrence Weed developed the first rudimentary EHR system, called the Problem-Oriented Medical Information System. Although revolutionary at the time, it would take some time before the EHR was adopted by nearly all hospitals throughout the UK.

### **2. 80% of health data is 'unstructured' – stored in its native or raw form, in hundreds of formats such as lab results, images and medical transcripts.<sup>2</sup>**

### **3. In 2020, it is estimated that the digital universe reached 40 zettabytes of data – that is equal to 5,200 gigabytes (GB) of data for every person in the world.<sup>3</sup> Considering most modern smartphones hold 64 GB of data – that is the equivalent of 81 full phones for every person in the world!**

### **4. The use of Big Data analytics (massive volumes of information created by digital technology that collect patient records) could reduce pharmaceutical R&D costs by as much as \$70 billion.<sup>4</sup>**

Data analytics lower administrative costs to the hospital and reduces the cost to the patient. Statistical data shows that administration currently contributes to 25% of healthcare costs, as humans are required to perform administrative tasks.

### **5. Health data can help to facilitate medical diagnoses.<sup>5</sup>**

Electronic health records can help healthcare professionals make informed clinical decisions, making all prescribed medicine, lab test reports and the medical history of a patient accessible through a single screen. This can help these professionals see the full picture of a patient's condition, allowing them to give more accurate diagnoses and better care.



- 6. Health data sharing can help make health systems more responsive and sustainable.**<sup>6</sup> Digital health technologies can improve access to health services, reduce costs, improve quality of care and make health systems more efficient, while allowing patients to care for themselves. For example, remote monitoring devices like smart watches can help people to better manage their own health, thereby reducing the burden on health systems and increasing their sustainability.
- 7. Digital health data can help to reduce inequalities in health.**<sup>7</sup> Digital healthcare can offer remote medical services, serving people who live in isolated areas by providing access to medical services that may not otherwise be available or affordable. Digital health systems can promote health literacy by educating the public on how to maintain healthy habits, thus promoting healthy behaviours and providing access to support networks for patients, helping to reduce health inequalities throughout the world.
- 8. The quantity of health data has grown at an explosive rate of 878% since 2016** and is continuing to grow exponentially, according to statistics compiled from Dell EMC.<sup>8</sup>
- 9. Digital health data can reveal information about health factors outside of those measured in a clinical setting,** such as data concerning diet and happiness levels.<sup>9</sup> This data can help to fill the gaps in current research and provide valuable information outside that gathered in clinical trials, thus improving the quality of research.
- 10. Health data collection can help to monitor your stress levels.**<sup>10</sup> Some smart watches come with an electrodermal activity (EDA) sensor that measures electrical activity in the skin, which can be used to compute your stress levels. Apps can also be used to encourage regular deep breathing and meditation that can decrease stress levels and improve the quality of your sleep.

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