



# Data Saves Lives

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**#DataSavesLives**



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# Introducing Data Saves Lives

Data Saves Lives is multi-stakeholder initiative led by the **European Patients' Forum (EPF)**.

Our aim is to raise wider patient and public awareness about the importance of health data, improve understanding of how it is used and establish a trusted environment for dialogue on this issue.



# Why DSL?



- To truly harness the power of health data, it needs to be **shared** and **used effectively** and **responsibly**.
- Scaling up the use of health data has **great potential to improve the quality of healthcare** and accelerate health research.
- There is an **acknowledged gap** in patient and public awareness about the importance of health data and understanding of how it is used.
- There is the need for a trusted environment for **multi-stakeholder dialogue** about responsible use and good practices across Europe.

# Responsible use of health data



The use (for both primary and secondary use) of health data has the potential to improve the wellbeing of citizens, make our healthcare systems more effective, data-driven and easier to use, speed up scientific research, and make healthcare services more sustainable and affordable for all EU citizens.

■ *But, the use must be **responsible**:*

- do no harm, protect patient privacy, build trust in the healthcare system, ensure transparency, respect the ethical and legal use of sensitive medical information, empower and engage patients, utilise healthcare data to **improve outcomes for the patients**.

- Advance the understanding of diseases
- Personalised healthcare & more accurate diagnoses
- New and quicker medicines and devices

Enhance the quality, safety, and sustainability of care, and transform healthcare into a more participatory process



How does Data Saves Lives get people talking about health data?

# Bootcamp training events

## Overview

In October 2022, we launched our very first DSL Training Bootcamp. Over two days, we equipped 17 regional and national level organisation representatives with practical tools and tips on how to advocate for and have informed dialogue around health data sharing. From the basics of health data terminology to the latest EU legislation, we explored the key challenges and questions many patient groups face within their communities to help them build confidence and knowledge in this area.

In March 2023, the second ever Data Saves Lives Training Bootcamp was held on Artificial Intelligence (AI). Over the two days, the group explored the basic principles, terminology, governance, and legislation of AI in addition to discussing working examples through interactive workshops - all with guidance from AI and communications experts.

On 5-6 December 2023, the third Data Saves Lives Training Bootcamp was held in Brussels, Belgium, in partnership with the European Health Data & Evidence Network (EHDEN). The bootcamp centred on the process of establishing community-led patient registries. The ultimate aim was to empower participants with insights into the steps involved and the pivotal role of patient groups in shaping registry design for community benefit.

On 8th March 2024, the "H2O in Austria - Putting Patients at the Center" event, hosted by EPF and the National Health Observatory Austria, will facilitate dialogue among patient organisations and representatives regarding responsible use of health data. Through the H2O Project and Register, participants will explore innovative approaches to improving patient outcomes while prioritising data security and privacy.





# Supporting longevity through a dedicated Data Saves Lives Toolkit

The DSL toolkit equips patient groups and health influencers 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.



<b>Part One:</b> <b>Health data 101: understand and communicate about the power of health data</b>	
INTRODUCING YOUR DATA SAVES LIVES TOOLKIT	Section 01
EXPLAINING HOW DATA SAVES LIVES	Section 02
ENGAGING WITH DIGITAL HEALTH TOOLS – CHECK BEFORE YOU CLICK	Section 03
CONVEYING YOUR MESSAGE: COMMUNICATING EFFECTIVELY WITH YOUR COMMUNITY	Section 04
SUPPORTING HEALTH DATA INITIATIVES: SHOULD YOU ENGAGE? A RISK ASSESSMENT TOOL FROM DATA SAVES LIVES	Section 05
DATA SAVES LIVES <b>TEMPLATE WEBINAR AGENDA</b> AN 'INTRODUCTION TO HEALTH DATA'	Section 06
DATA SAVES LIVES <b>TEMPLATE SURVEY</b> TO UNDERSTAND PATIENT AND CARER CONFIDENCE IN HEALTH DATA-SHARING	Section 07
<b>10 THINGS</b> YOU MAY NOT KNOW ABOUT HEALTH DATA	Section 08

<b>Part Two:</b> <b>AI: from science fiction to science fact</b>	
INTRODUCTION	Section 01
WHAT IS AI AND HOW COULD IT BENEFIT PATIENT COMMUNITIES?	Section 02
KEY REGULATIONS/GUIDELINES	Section 03
AI AT WORK: FROM PREVENTION TO REHABILITATION	Section 04
GETTING TO KNOW THE STAKEHOLDERS	Section 05
TELLING THE STORY OF AI	Section 06
HOW TO COMMUNICATE WITH DIFFERENT AUDIENCES	Section 07
TEMPLATE QUESTIONS FOR DEVELOPERS	Section 08
GATHERING INSIGHTS	Section 09
TIPS FOR FINDING FUNDING OPPORTUNITIES	Section 10
LOCALISING DATA SAVES LIVES	Section 11
KEY TERMINOLOGY	Section 12



**Toolkit 3.0 is now online:**  
<https://datasaveslives.eu/toolkit>

# An eye to the future



DSL 5th anniversary: *“It's all about Data”*

## ***What can the participations gain?***

- An awareness of the important role health data literacy plays in communicating the benefits of health data to the community
- Confidence to handle challenging questions from the community about the European Health Data Space
- Confidence to respond to collaboration requests and to assess whether to engage in an opportunity
- An understanding of how patient groups can position themselves as true partners in health data projects and the development of digital health tools to improve outcomes for people living with disease
- An understanding of the potential benefits of AI and the role of patient groups in influencing how Artificial Intelligence is designed
- An understanding of the benefits of community-governed patient registries and how they can be established
- An opportunity to learn from peers including from those who have localised DSL in their regions.



# There is no responsible use of data without patients' literacy!



When it comes specifically to digital health literacy, it is important that patients understand the new tools as these new technologies are translated into clinical practice. With the legislative proposal for a EHDS now on the table, improving people's digital health literacy is essential to empower them to harness the full potential of the new framework designed to improve patients' access to and control of their health data.

**EHDS toolkit for patients and patient organisations**

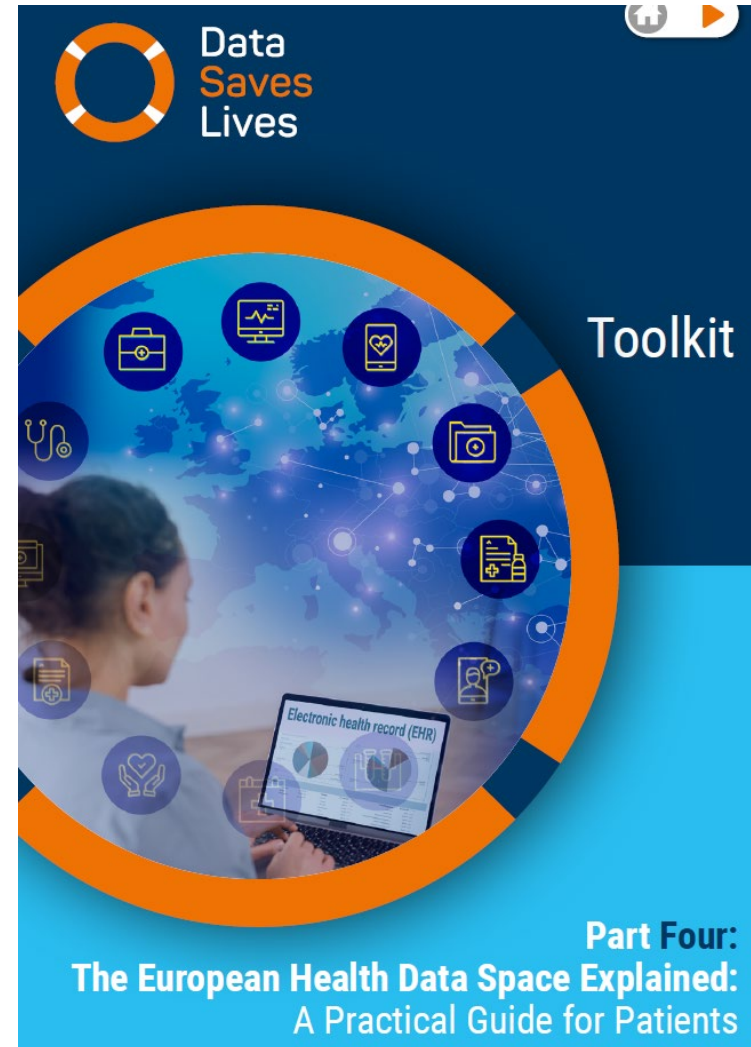
# EHDS Toolkit

EPF is in the process of drafting an EHDS toolkit for patients and patient representatives – **Data Saves Lives initiative**

It will be:

- Free of charge
- In lay languages
- Translated in several EU languages
- Adaptable to national and regional contexts
- Expandable

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# Follow our journey & get in touch



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