



Data  
Saves  
Lives

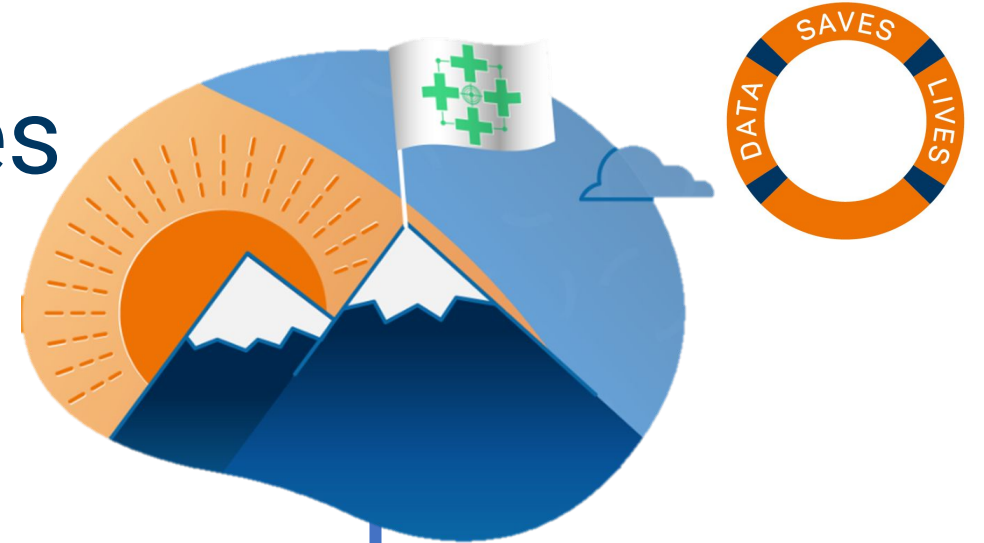
#DataSavesLives

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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.



# Putting the patient voice at the heart of healthcare



Data Saves Lives exists to:



Help drive recruitment in clinical trials



Support the development of patient registries and generate real-world insights



Help foster relationships with industry partners to improve patient care

Data Saves Lives is a **trusted and independent voice** as part of the European Patients' Forum, which is an umbrella organisation representing **78** patient groups in **19** countries and an estimated **150 million** patients across Europe

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# Bootcamp training events

In October 2022, we launched our very first DSL Ambassador 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 Ambassador 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.

In December 2023, we will have our 3<sup>rd</sup> bootcamp in partnership with EHDEN (European Health Data Evidence Network – IMI project) on “Establishing a community-governed





# Data Saves Lives Toolkit – New AI

New content includes:

- Artificial Intelligence (AI) 101
- Key regulation
- Key terminology
- AI at work: from prevention to rehabilitation
- Communication about AI

Each section has “how to” guide added

The digital version of the toolkit is here: <https://datasaveslives.eu/toolkit>

# Data Saves Lives Germany



## Overview

Data Saves Lives Germany is the first off-shoot of the main campaign, providing patient organisations within the region, a dedicated hub to access the translated information and materials they need to have a positive dialogue about health data with their communities.

With ongoing counsel and support, we hope that this is the first of many regional initiatives that go on to carry the DSL torch and bring the benefits of health data to more people.







# Follow our journey & get in touch



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