



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	Introduction and housekeeping	Host
10 mins	What is electronic health data? And who benefits from health data sharing and how?	Expert speaker
10 mins	What data protection measures are needed to protect the privacy of individuals when sharing health data?	Data privacy expert speaker
10 mins	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	Patient organisation representative
50 mins	Open forum discussion <i>Example facilitator questions (to be posed to the expert panel or to the audience):</i> <ul style="list-style-type: none">• 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?• How do you think patient groups can best communicate the benefits of health data sharing?• Implementing data security measures can be seen as cumbersome, very technical and requiring a lot of time. How would you respond to this?• Are there any existing practical resources that would help to overcome perceived challenges of implementing required data protection measures?	Host / independent facilitator
5 mins	Round up	Host