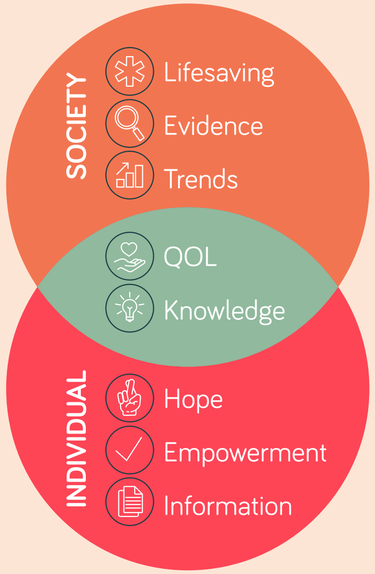
EUROPEAN PATIENT INNOVATION SUMMIT 2021

Why data matters: the EPIS community perspective

Outcomes from EPIS 2021 Webinar #1, 9th September 2021[1]

Data matters to all **digital health stakeholders** – it brings value to patient organisations, patient communities, health systems and society at large. Data also matters to **individual patients**, but **their voice isn't always heard in relation to how their personal data is collected, used, stored, and shared with them.**



What is the value of health data for society and individuals?

Patient representatives were asked about the value of health data for society and for the individual. Their response shows that some of the benefits of health data for society and for the individual are **in fact similar and interlaced**.

For both society and individuals, health data is key for **knowledge and quality of life (QoL)**. For example, **data from wearables** can be fed into computational models to **predict health status changes** and eventually **improve QoL**. Hackathons in cancer care **can inform our collective knowledge** for future patients following the same cancer treatment path.

> *We do not want to do something for or to patients, but **with** them. We want to encourage individuals to be empowered and, leveraging latests scientific methods in collaborative projects, to find solutions themselves*

Prof. Katarzyna Wac,
University of Geneva, Switzerland

> *The patient's challenge is collecting **data on treatments, tests, and experts to guide them in deciding on their treatment strategy and selecting among treatment options***

Brad Power,
Cancer Hacker Lab, USA

> *Many companies developed technologies without input from patient organisations, but there has been a major **shift towards partnering with the patient community** and asking the right questions to get at the issues that matter most to patients*

Marc Boutin,
Global Head of Patient Engagement, Novartis

> ***Our data is being kept from us** and we will only see the quality of the data once we have access to it [...] If patients see that their data is not in a format that can be used for research...then they will not appreciate the value of their data fully or be motivated to get engaged in research.*

Gilliosa Spurrier-Bernard,
Melanome France, France

If the patient community was in charge of health data, what would be different?

The future of health data

EPIS Webinar panellists flagged the need to:

- Push for policy change in Europe with regard to data handling, with more control given to the individual
- Make more tools available for individuals to collect their data from multiple institutions and share it with whomever they wish
- Gather data only when needed – it must aim to improve QoL and build our collective knowledge

Footnotes: 1. The EPIS 2021 Webinar #1 was attended by over 290 community members across 40 different countries, including those in Europe, Africa, Asia, North and South America.

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