



fighting heart disease  
and stroke  
european heart network

# European Heart Network

**Data Standards Workshop**

**Patient & Consumer perspectives**

**18 May 2021 | Virtual meeting, EMA**

EHN is a not-for-profit, non-governmental organisation independent of political parties and economic interests.  
EHN is funded by its members and receives no funds from any industry.



fighting heart disease  
and stroke  
european heart network

## About EHN

The European Heart Network represents foundations and patient associations active in cardiovascular disease.

EHN is a member of EMA's Patients and Consumers Working Party and EMA-HMA Big Data Steering Group.





fighting heart disease  
and stroke  
european heart network

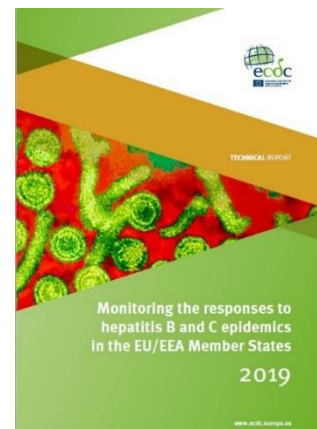
# Needs

A mandatory minimum standards framework is a prerequisite for data quality

Data Privacy and Security *by design*

A federated system

Transparency





fighting heart disease  
and stroke  
european heart network

# Top themes

- Data quality
- Secondary use of data for studies (e.g. clinical trials)
- Artificial intelligence



EUROPEAN BEST INFORMATION THROUGH REGIONAL OUTCOMES IN DIABETES

---





fighting heart disease  
and stroke  
european heart network

# Acknowledgements

Thank you for your insights!

- European Liver Patients Association
- International Diabetes Federation Europe
- BigData@Heart project



fighting heart disease  
and stroke  
european heart network

# Thank you

**Marilena Vrana**

mvrana@ehnheart.org

<http://www.ehnheart.org/>

EHN is a not-for-profit, non-governmental organisation independent of political parties and economic interests.

EHN is funded by its members and receives no funds from any industry.