



fighting heart disease
and stroke
european heart network

European Heart Network

EU Big Data Stakeholder Forum

Patients perspectives

15 December 2020 | 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.



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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.





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Patients acknowledge the value of Big Data and Digital technologies

Patients are generally open to and understand the benefits of data sharing.

Personal investment
towards the 'common good'



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Priorities

- A European-wide infrastructure
- Modernise the regulatory framework
- Meaningful collaboration of all stakeholders
- Security and accountability
- Transparency



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Opportunities

- Identify areas of (people's) unmet need
- Conduct more targeted clinical trials
 - Patient selection
 - High impact but lower cost
- Improve access to safe and effective innovations
- Ensure monitoring of efficacy and safety of new treatments
- Conduct trials on repurposing medicines



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Risks

- Technology- / industry- driven vs patient-centred research and innovation
- Privacy and data security concerns
- Unequal digital literacy
- Lack of personal motivation
- Accessibility - inequalities



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Areas for collaboration

Co-creation is
key!

*Patients' real needs
are key to factor-in
from the outset to
ensure relevance,
value, efficacy and
trust.*

- Social licencing
- Ethics and security
 - Regulatory / governance framework
 - Transparency
 - Equal access
- Data Quality
- Skills: Digital literacy



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Thank you

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