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Citizen Science in Healthcare

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+ 1–2% of GDP until 2060

Healthcare expenditure for aging population and chronic diseases

–20 million by 2025

Expected shortage of labour supply in healthcare services

= more sustainable models

In healthcare in the EU



Different Forms of CS

Crowdsourcing

Invite citizens to perform a task or solve a problem

Participatory Health Research

Engage those who are affected in a collaborative and empowering process

Crowdsourcing and Patient Networks: Main Usages

**Problem
Solving**

**Data
Processing**

**Surveyance
/
Monitoring**

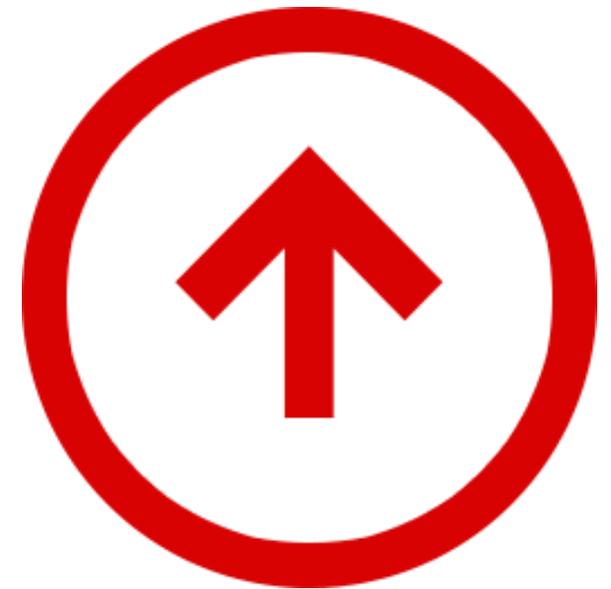
**P2P
Network**

Success Case: PatientLikeMe

- ▶ PatientsLikeMe (amyotrophic lateral sclerosis [ALS], Multiple Sclerosis [MS], Parkinson's Disease, human immunodeficiency virus [HIV], fibromyalgia, etc.).
- ▶ Goal: help patients answer the question:
- ▶ *Given my status, what is the best outcome I can hope to achieve, and how do I get there?*

Trend

- ▶ Patient and user-generated healthcare data are expected to further increase in the coming decade



Future

- ▶ New means of investigation in a multi-tier ecosystem:
 - ▷ Crowd self-experiments
 - ▷ Participant-led research (already happening in aging research)
 - ▷ Researcher-led studies

Impact: Example

- ▶ Expand the scope of medicine from the traditional focus on treating disease to personalized preventive medicine

Recommendations

- ▶ Data Quality:
 - ▷ Support for scientifically valid CS in healthcare
- ▶ Data Privacy:
 - ▷ Clear guidelines for legal, ethical, commercial and privacy issues that arise in CS in healthcare

References

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- ▶ Swan M. (2012). Crowdsourced health research studies: an important emerging complement to clinical trials in the public health research ecosystem. *J Med Internet Res*. Mar 7;14(2):e46. doi: 10.2196/jmir.1988

THANKS!

Any questions?

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