Medical citizen science:

From data awareness to advocacy!

METIS online lecture, June 5, 2026

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Open, social learning

METIS

Follow us!

Web2Learn: 10+ years innovating in digital education

- Established in 2014.
- We develop:
  - e-learning services.
  - Customized software solutions to address digital education needs.
- Active in EU grants (Erasmus+, Horizon Europe, national funds).

Areas: professional training, citizen and open science, social innovation

15 ongoing EU-funded projects

> 3000 end users reached

Sectors: Higher Education, VET, School Education, Adult Education

The science starts with you:
3 quick polls!

An empowering approach in advancing health science!

- Science “for the people” and “by the people”!
- An empowering pathway for both **citizens** and **science** built through public participation in health research (MCS).
- Multipurpose potential of MCS that advances:

  a) health research;

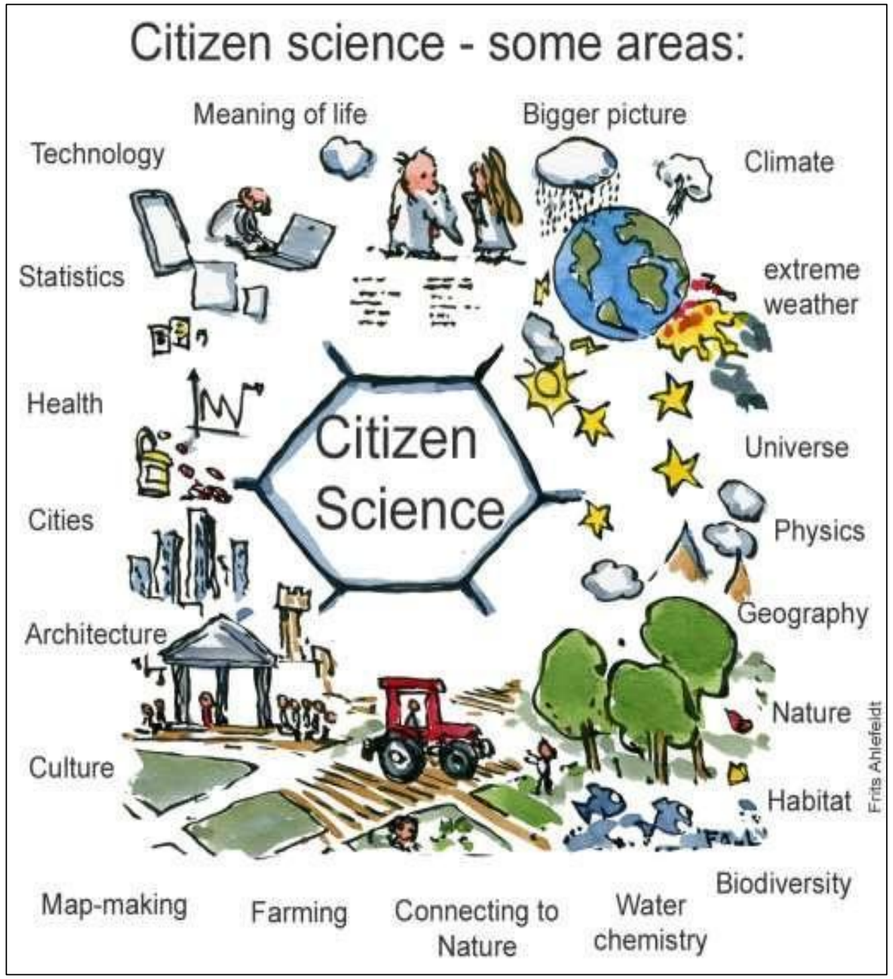
  b) health literacy;

  c) patient-driven advocacy, and

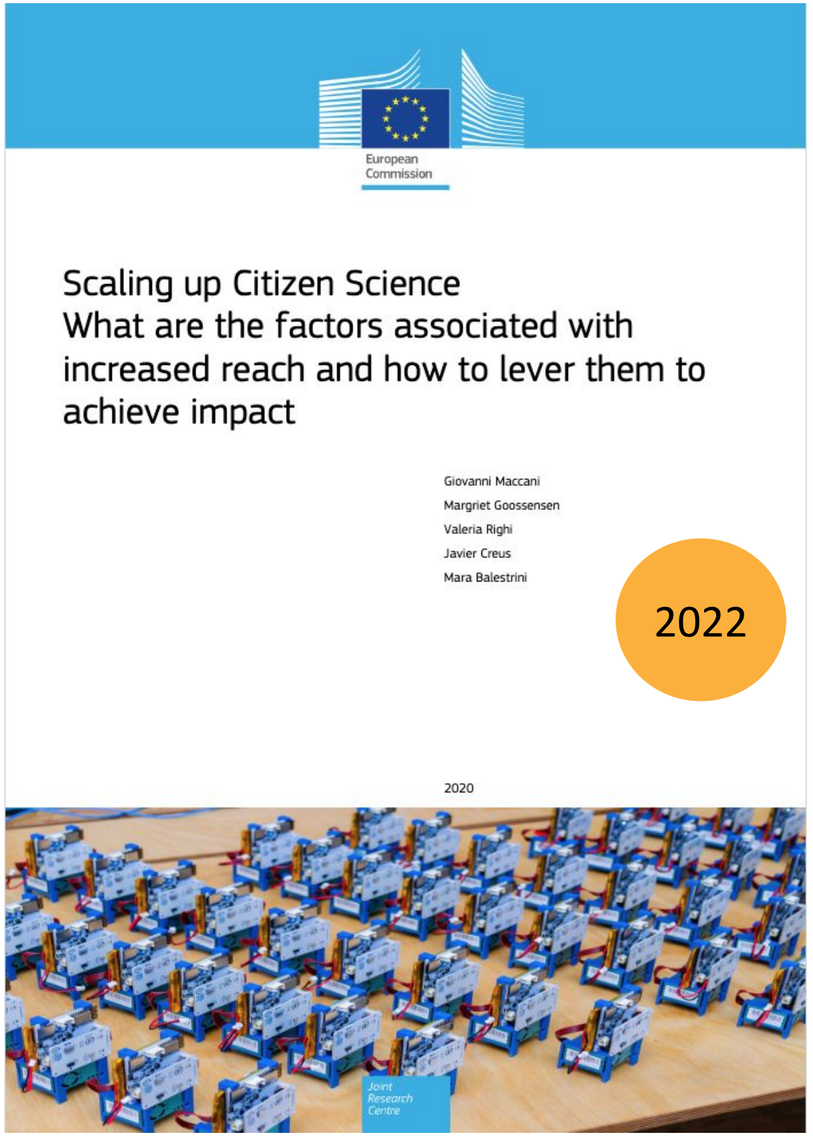
  d) interdisciplinarity in health science.

What is citizen science (CS)?

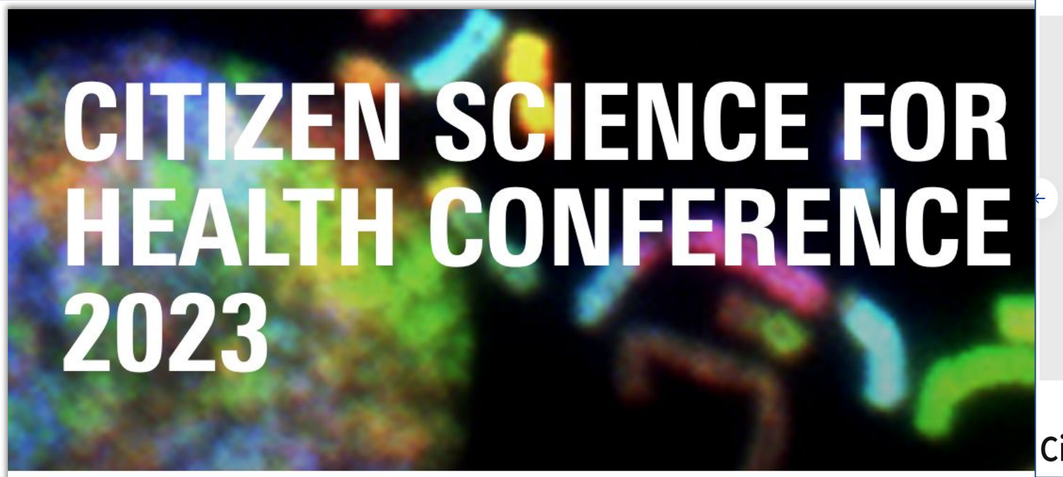
- **Collective action** that brings together citizens and researchers-scientists.
- Citizen groups collaborate with scientists by providing **observations, recording data and/or analyzing** them.
- 10 CS Principles (ECSA, 2015).



Citizen science high on the EU agenda



Citizen science for health expert groups



THE FIRST INTERNATIONAL **CITIZEN SCIENCE FOR HEALTH CONFERENCE** WAS A GREAT SUCCESS!

Citizen Science for Health 2025

ecsa

European Citizen Science Association | Working Group

Citizen science for health

Health is relatively under-represented in citizen science, despite the fact that it is a very diverse and promising domain. Projects and approaches may range from applications in the domain of public health, to personal science approaches associated with the Quantified Self movement, and every shade in between. At the same time, the engagement of patients in health research has a long tradition, even though their impact on e.g. decision making on research questions, methodology, ethics, analysis and data management remain limited so far. Citizen Science has a huge potential contribute to innovative health research, as well as to society.

This Working Group believes that to unlock this potential there is a need to collaborate more intensely across borders and domains. The purpose of the Working Group is hence *to increase the social and scientific impact of citizen science for health.* Its main objectives are:

https://www.ecsa.ngo/working-groups/citizen-science-for-health/

Understanding medical citizen science (MCS)

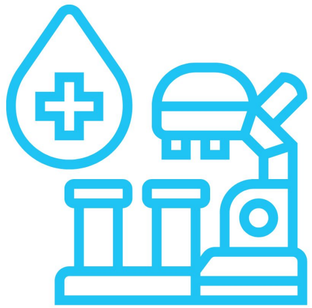
Medical citizen science

Definition: Ordinary citizens who participate in health research processes and programs. Usually, their participation lies in data collection for scientific and research communities.

Citizens → Not exclusively patients.

Scope: Advance health research for the benefit of society.

Researchers + Citizens → Medical Citizen Science



Fiske A, Prainsack B, Buyx AMeeting the needs of underserved populations: setting the agenda for more inclusive citizen science of medicine. *Journal of Medical Ethics* 2019;**45:**617-622.

Citizen science in health: From N-of-1 to N-of-many-1's

- Public participation manifested first through community-based participatory research (CBPR) to address health inequalities.
- Similar forms of community science: "popular epidemiology" and "community-based health assessments."
- 21st century citizen science: **observational** & **interventional** research.

N-of-1 known as health self-tracking e.g. investigating diets, sleep patterns, medicine

N-of-We, Community-driven health inquiries e.g. PatientsLikeMe platform

N-of-many-1's Standardized methods & analyses by professional scientists.

Wiggins, A., & Wilbanks, J. (2019). The Rise of Citizen Science in Health and Biomedical Research. *The American Journal of Bioethics*, *19*(8), 3–14. https://doi.org/10.1080/15265161.2019.1619859

Similar terms and common objectives

Common objectives:

- Public engagement in health research.
- Democratisation of science.
- Advancement of research breakthroughs.

patient science, patient-oriented research, patient engagement in research, participatory health research, patient and public involvement, personal science

Indicative bibliography

Heyen, N. B., Gardecki, J., Eidt-Koch, D., Schlangen, M., Pauly, S., Eickmeier, O., Wagner, T., & Bratan, T. (2022). Patient Science: Citizen Science Involving Chronically Ill People as Co-Researchers. *Journal of Participatory Research Methods*, *3*(1). https://doi.org/10.35844/001c.35634

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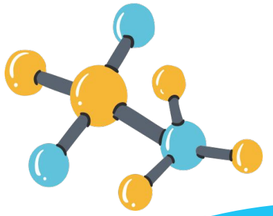
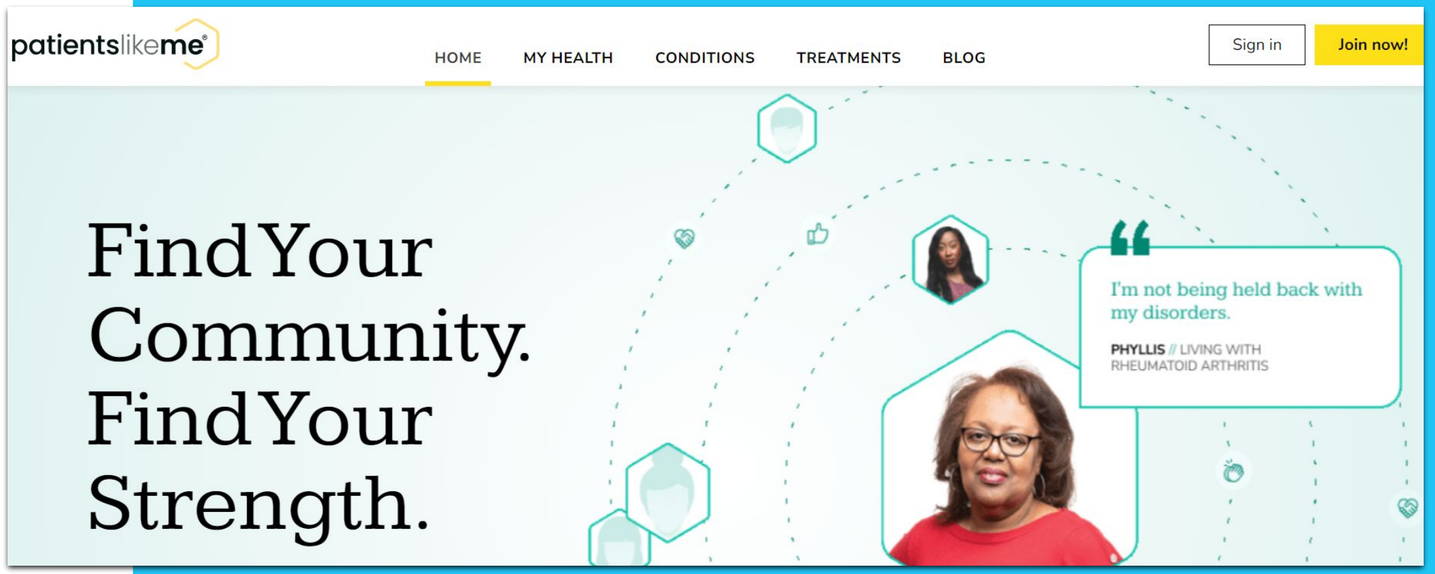
Citizens revolutionizing the way health science unfolds



A. Communities of patients sharing health data to advance research and medical solutions!

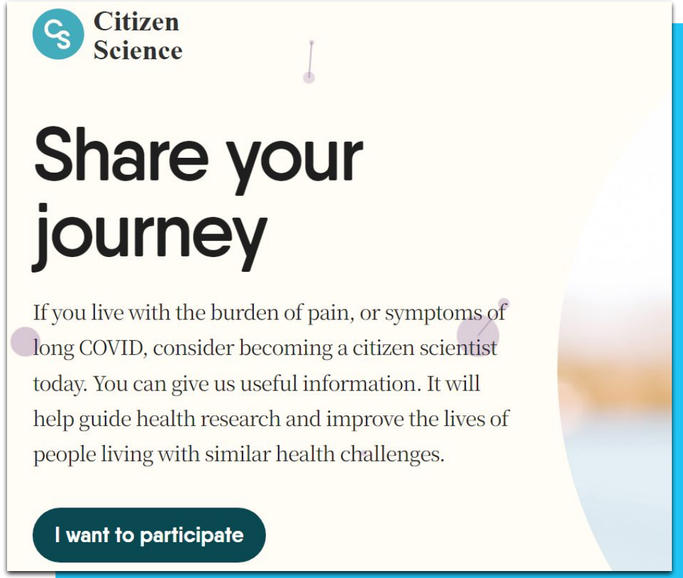
PatientsLikeMe

- Over **850.000** engaged users.
- **70** communities covering **2.800** conditions (cancer, heart attack, hair failure, etc.)



Citizen Science for Covid

- **15.000** data points.
- Comparing data via **4** indicators



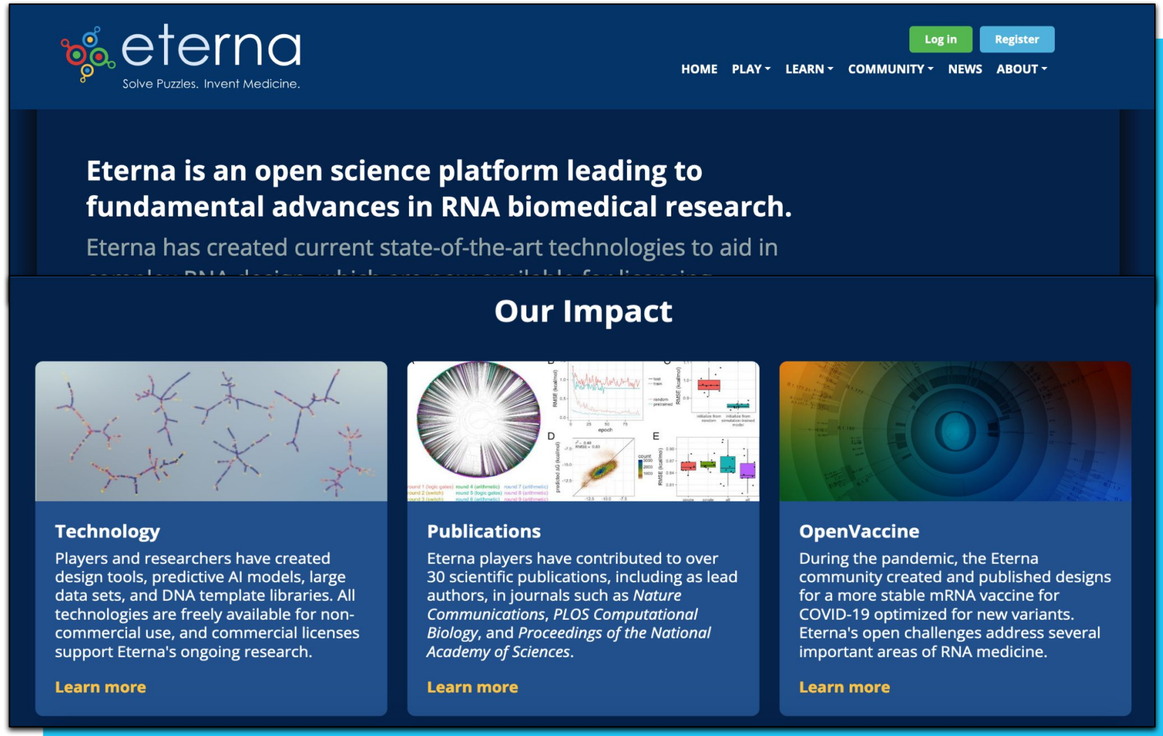
B. Communities of users engaged in open health research-massive open online gaming communities!

Genigma

- **39.543 unique users** engaged!
- In 20 weeks, **600.287** solutions collected

Eterna

- **> 100 user groups** engaged!
- Contributions to **over 30** science papers



Why it matters?

MCS ensures that health research is

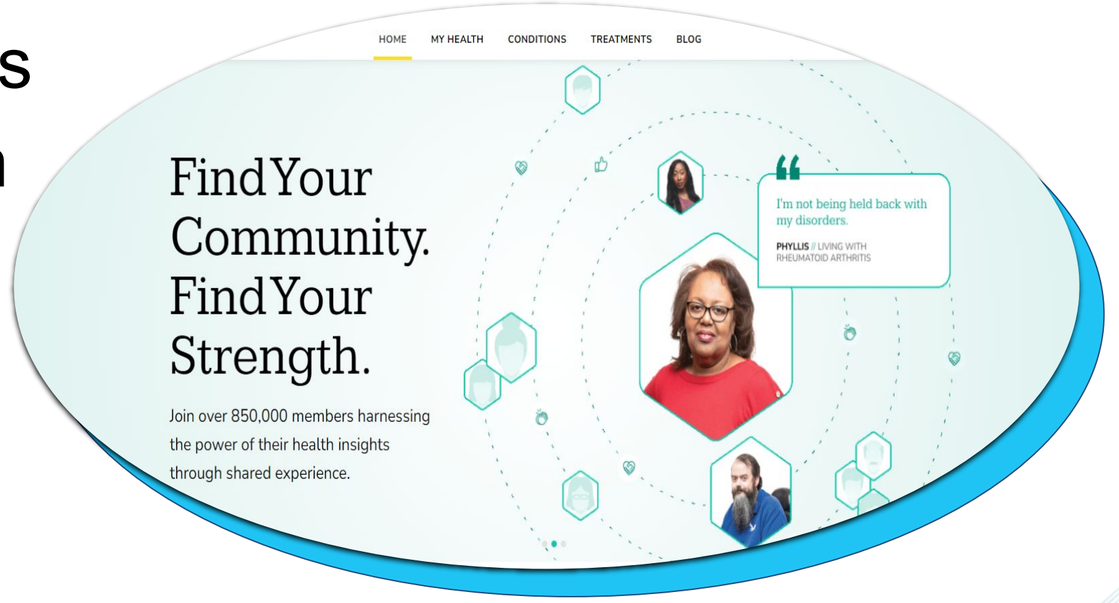
- socially relevant;
- appropriate and comprehensive (especially its tools);
- acceptable and feasible;
- **actionable** (define strategies, next steps)!

Colomer-Lahiguera, Sara et al. "Patient and public involvement in cancer research: A scoping review." Cancer medicine vol. 12,14 (2023): 15530-15543. doi:10.1002/cam4.6200

MCS platforms

PatientsLikeMe

- Leading participatory health platform (850K users).
- Personal data and shared stories by users
- Doctors-patients-researchers cooperation
- Scholar impact: **100 studies in peer-reviewed medical and scientific journals.**



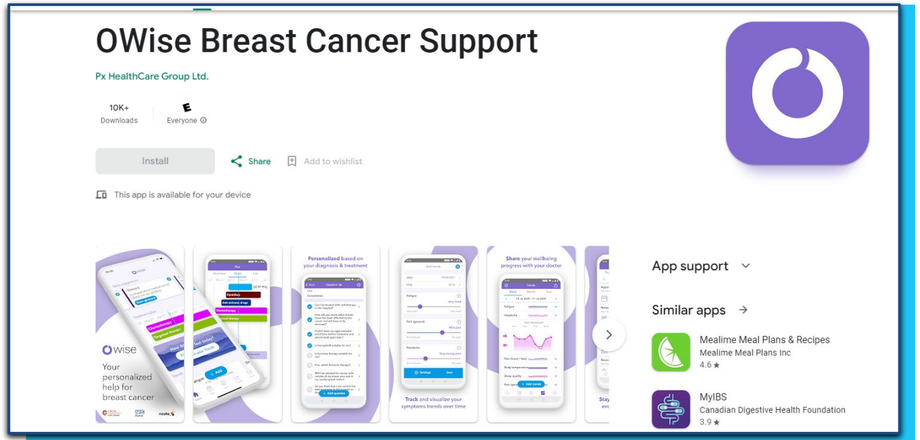
https://www.patientslikeme.com/

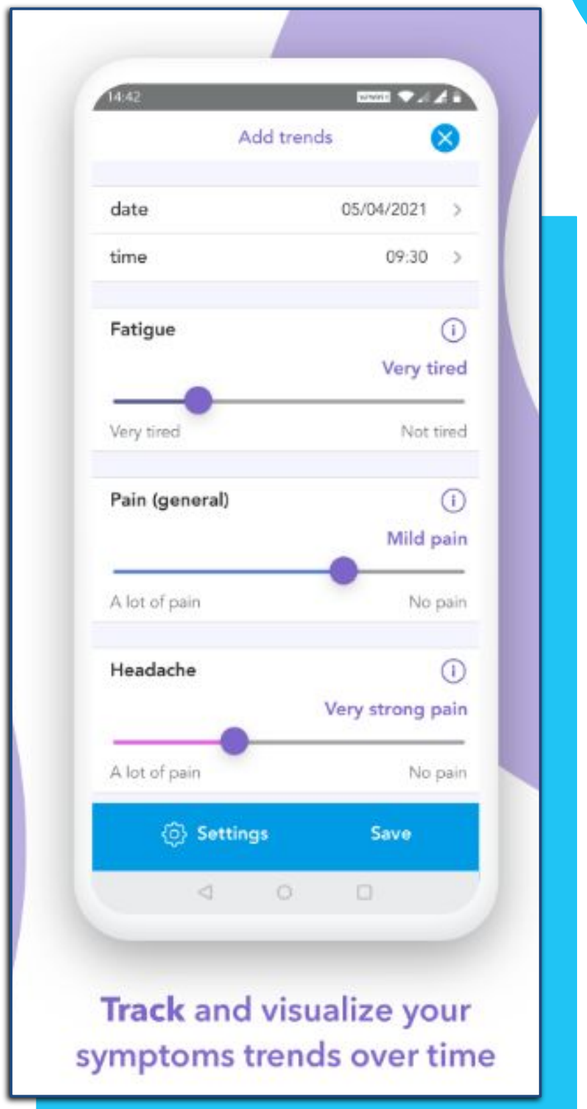
Citizen Science (for post-COVID 19)

- People with post-COVID symptoms sharing their struggles and healing journey.
- Data collected by researchers to better understand and treat post-COVID symptoms.
- Canada-based initiative open to users worldwide: https://patientscientist.ca/

OWise Breast Cancer Support app

- Self-tracking mobile app for breast cancer patients.
- The app provides information on symptoms to enhance awareness and health literacy of patients.
- **More than 10.000 downloads**
- Among top breast cancer apps (2021 study)



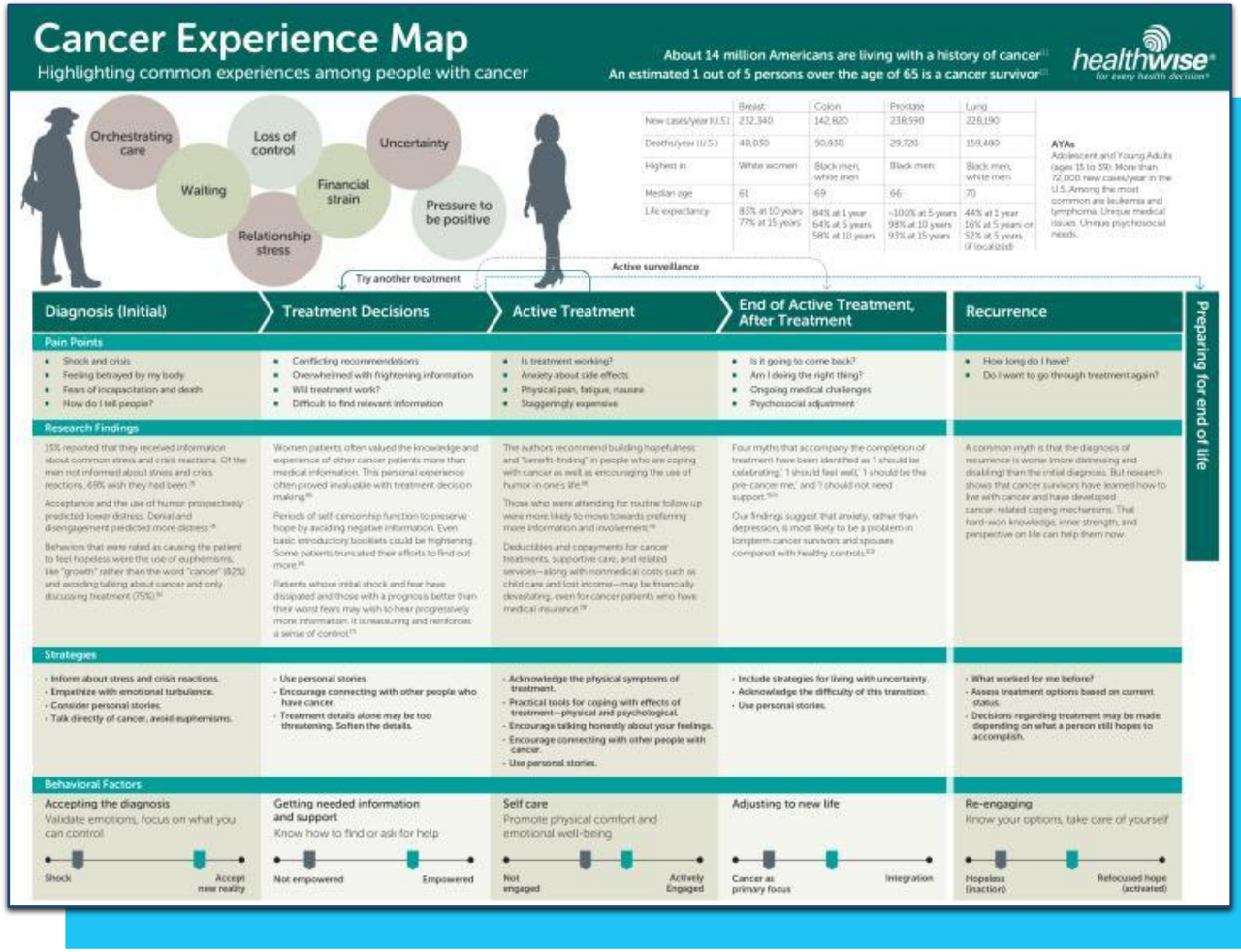


https://tinyurl.com/5n95r285

Cancer Experience Map

A tool for content developers to capture cancer patients' experiences.

"the map shows common overall themes for cancer patients, concerns at key treatment points, strategies for patient engagement, and targeted behavioral goals."



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Health data:

Privacy and ethics

Personal Health Data

"Personal Health Data (PHD) includes [..] data from consumers' encounters with the healthcare system as well as data generated when they consent to participate in clinical research. PHD may include individually identifiable (or re-identifiable) research results that investigators derive during informational research—research that uses people's data or biospecimens with or without their consent"

Evans, B. J. (2017). Power to the People: Data Citizens in the Age of Precision Medicine. *Vanderbilt Journal of Entertainment and Technology Law*, *19*(2), 243–265.

Privacy issues

- **Rethinking consent forms:** de-identified data that include anonymized and pseudonymous data (Cheung, 2018)
- **Privacy interdependence**: individuals' privacy is "affected by the decisions of others, and could be out of their own control." (Evans, 2017)

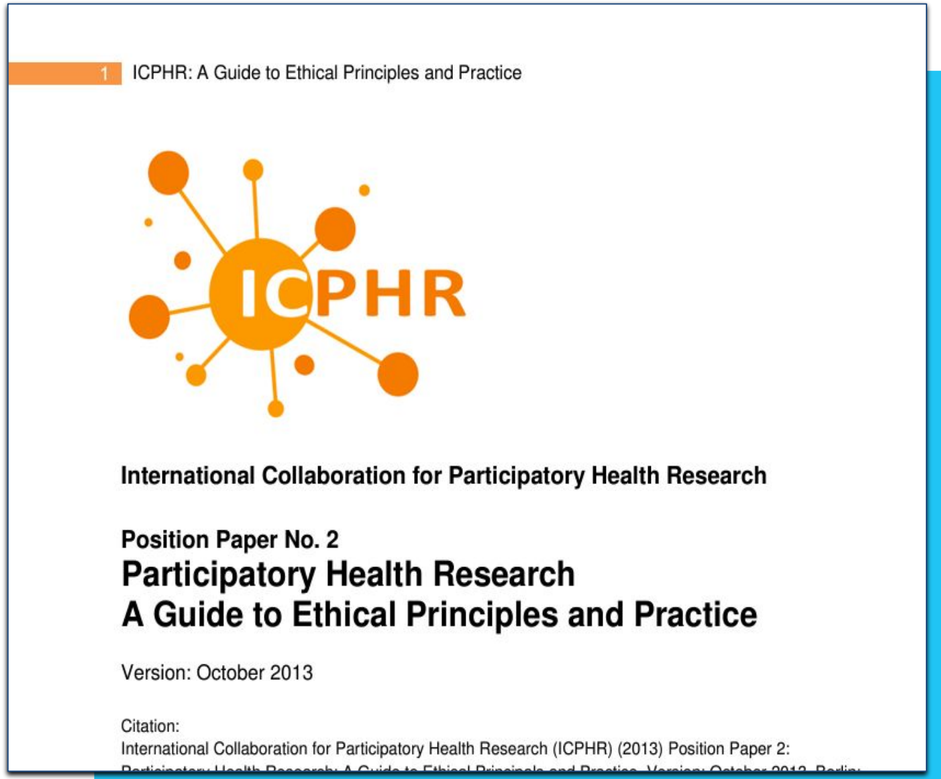
Evans, B. J. (2017). Power to the People: Data Citizens in the Age of Precision Medicine. *Vanderbilt Journal of Entertainment and Technology Law*, *19*(2), 243–265.

Cheung, A. (2018). Moving Beyond Consent For Citizen Science in Big Data Health and Medical Research. *Northwestern Journal of Technology and Intellectual Property*, *16*(1), 15.

Ethics

International Collaboration for Participatory Health Research=> Guide to ethical principles and practice (2013).

Concerns over data usage lead to alternative approaches like: Consumer-driven **health data commons** → institutional arrangements for organizing and enabling citizen research sponsorship!



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Citizen engagement and advocacy in health research

Improving health and patient care services through participation

- Citizen engagement may take place in several phases: *setting, planning, decision-making, implementation or evaluation*.
- **Target audiences**: patients, families of patients, informal caregivers, representatives from community organizations, members of the general public.

studies focused on primary, nursing and acute care found that patients are more interested in knowing about the quality of interpersonal interactions with health care providers."

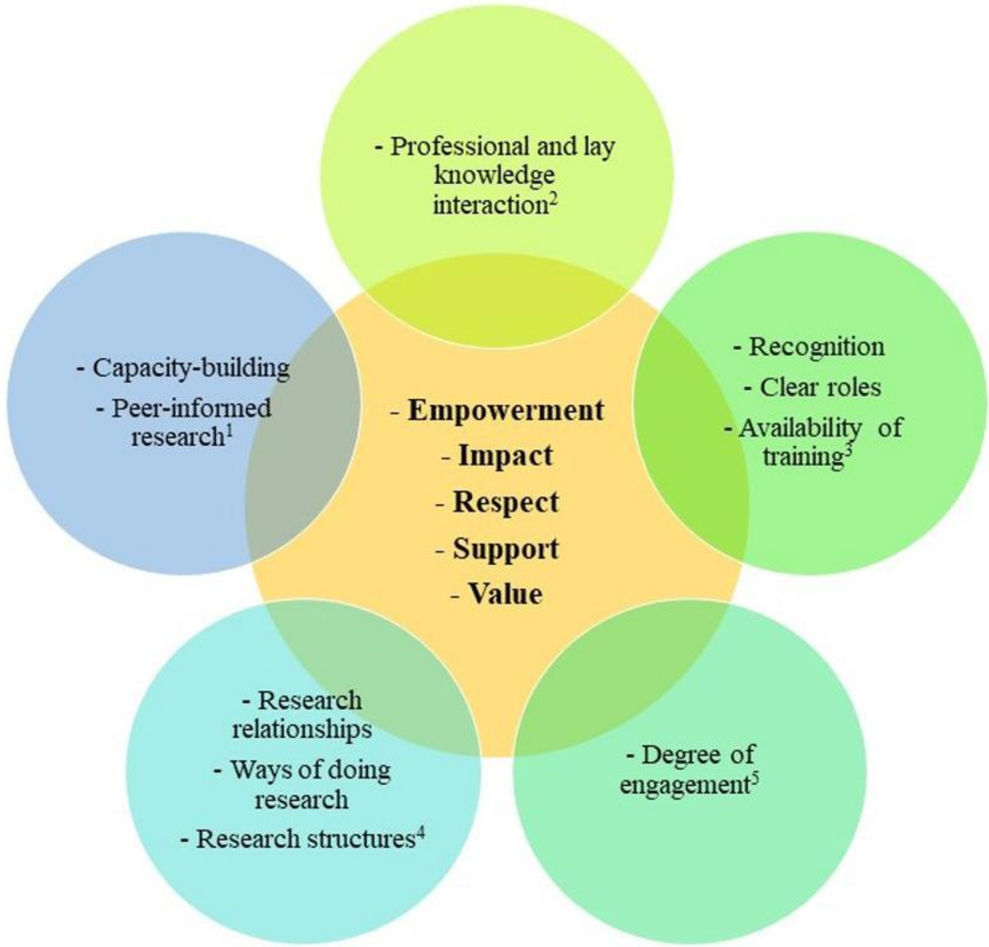
(Gagliardi et al., 2008)

Evaluating citizen engagement in health research

Measuring citizen engagement in a health project based on 5 indicators:

- Empowerment
- Impact
- Respect
- Support
- Value

Shahid, A., Lalani, I. N., Rosgen, B. K., Sept, B. G., Longmore, S., Parsons Leigh, J., Stelfox, H. T., & Fiest, K. M. (2022). A scoping review of methods to measure and evaluate citizen engagement in health research. *Research Involvement and Engagement*, *8*, 72. https://doi.org/10.1186/s40900-022-00405-2



*Shared features among all frameworks are highlighted in the middle (orange) circle.
[1]Greer et al.; [2]Gibson et al.; [3]Payne et al.; [4]Morrow et al.; [5]Oliver et al.

From patient engagement to advocacy

MCS for patient advocacy in cancer research.

A Spears, P. (2021). Patient Engagement in Cancer Research from the Patient's Perspective. *Future Oncology*, *17*(28), 3717–3728. https://doi.org/10.2217/fon-2020-1198

Key takeaways

- Medical citizen science transforms citizens and patients **from passive data providers into active agents** in health research.
- **Participatory approaches** make health research more relevant, inclusive, and impactful by **integrating lived experiences and community needs**.
- Responsible use of health data requires balancing openness and collaboration with privacy, ethics, and trust-building.

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