

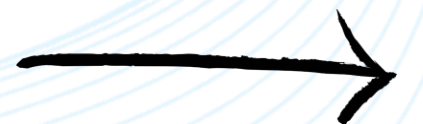
The role of citizens in innovating health

IAEA Regional Workshop on Hadron Therapy,
October 18-19, 2024, Thessaloniki, Greece

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Follow us!



Web2Learn: Innovating in citizen science for social good

- 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

16 ongoing EU-funded projects

> 3000 end users reached

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



Citizen engagement in health

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

Citizens → Not exclusively patients.

Multiple benefits for science and society.



Similar terms and common objectives

Common objectives:

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

citizen engagement in health, patient-oriented 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>

Rouleau, G., Bélisle-Pipon, J.-C., Birko, S., Karazivan, P., Fernandez, N., Bilodeau, K., Chao, Y.-S., de Pokomandy, A., Foley, V., Gagnon, B., Gontijo Guerra, S., Khanji, C., Lamoureux-Lamarche, C., Lebouché, B., Lunghi, C., Menear, M., Riverin, B. D., & Rodrigue, C. (2018). Early career researchers' perspectives and roles in patient-oriented research. *Research Involvement and Engagement*, 4(1), 35. <https://doi.org/10.1186/s40900-018-0117-z>

Smith, E., Bélisle-Pipon, J.-C., & Resnik, D. (2019). Patients as Research Partners; How to Value their Perceptions, Contribution and Labor? *Citizen Science: Theory and Practice*, 4(1). <https://doi.org/10.5334/cstp.184>

Marlett, N., Shklarov, S., Marshall, D., Santana, M. J., & Wasylak, T. (2015). Building new roles and relationships in research: A model of patient engagement research. *Quality of Life Research*, 24(5), 1057–1067. <https://doi.org/10.1007/s11136-014-0845-y>

Wright, M. T., Springett, J., & Kongats, K. (2018). What Is Participatory Health Research? In M. T. Wright & K. Kongats (Eds.), *Participatory Health Research: Voices from Around the World* (pp. 3–15). Springer International Publishing. https://doi.org/10.1007/978-3-319-92177-8_1

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”



CITIZEN SCIENCE FOR HEALTH CONFERENCE 2023

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



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.

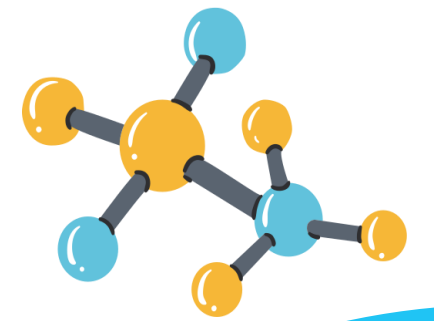
This Working Group believes that to unlock this potential there is a need to collaborate more intensely across borders and domains. The purpose of the Working Group is hence to *increase the social and scientific impact of citizen science for health*. Its main objectives are:



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



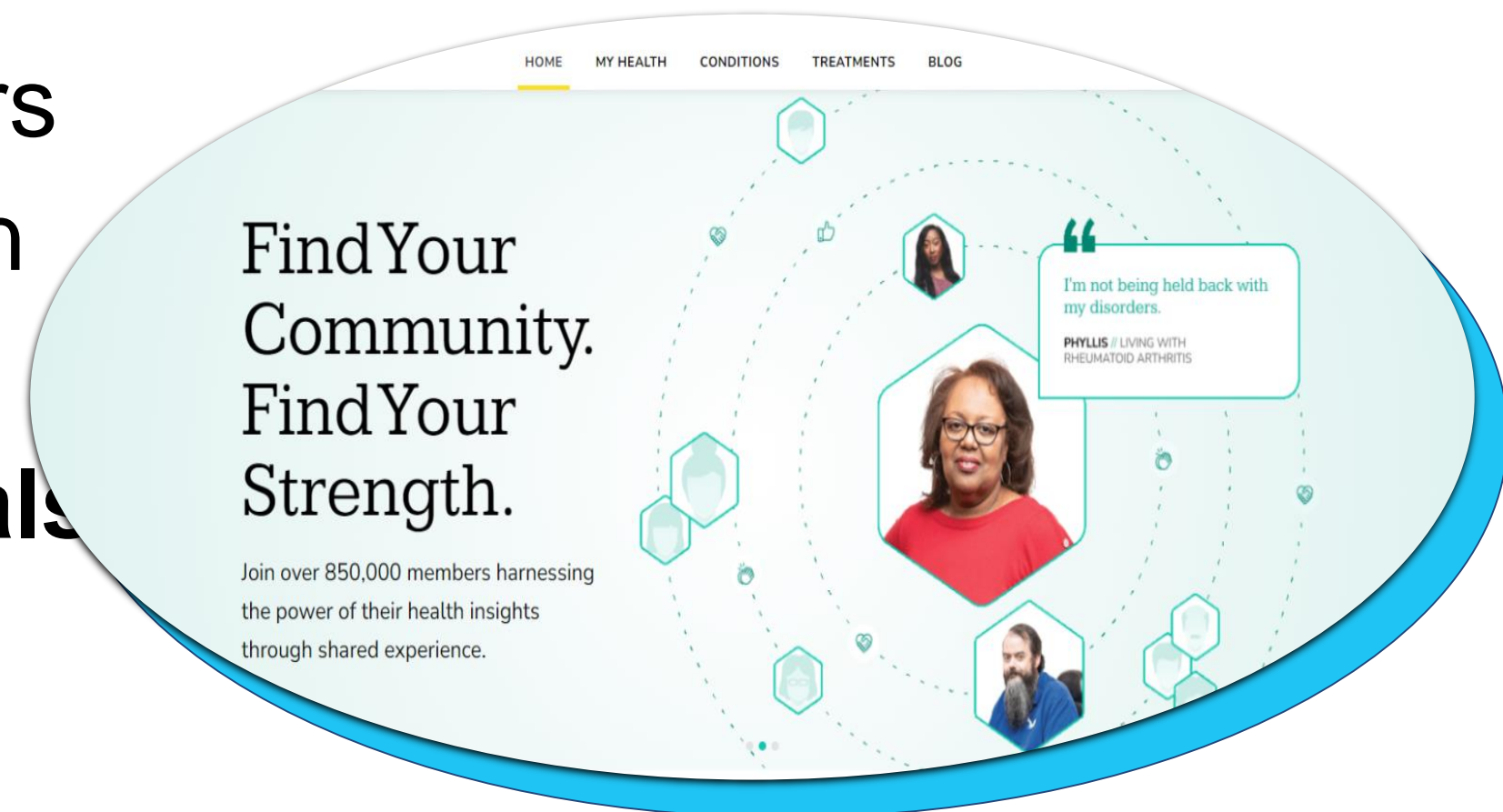
**Citizens revolutionizing the
way health science unfolds**



PatientsLikeMe

W21

- 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**



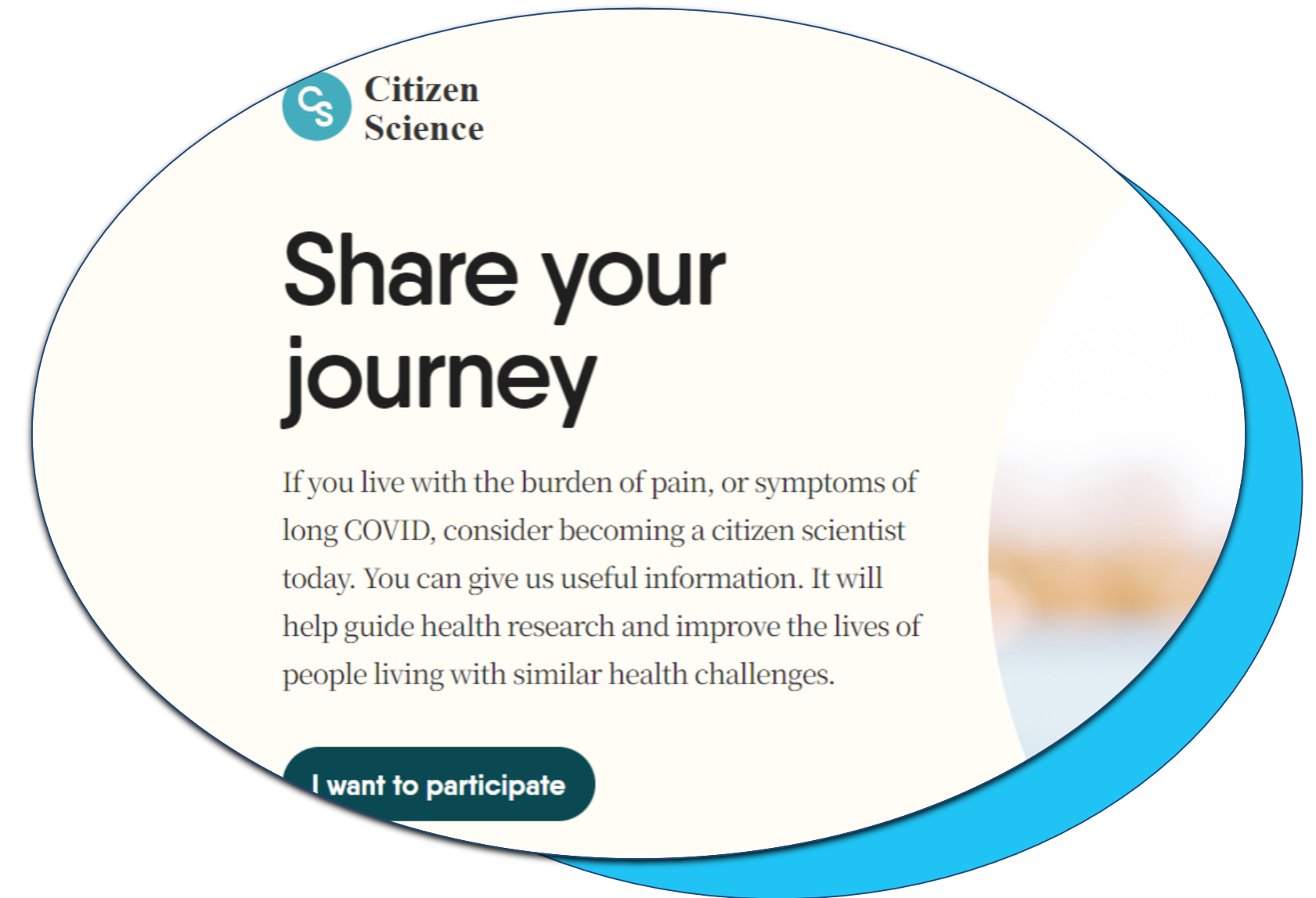
<https://www.patientslikeme.com/>


Citizen Science (for post-COVID 19)

W21

- 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/>

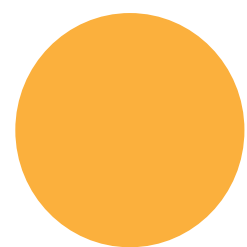
A graphic for Citizen Science featuring a large blue circle with a white background. The text is centered and includes a logo, a title, a paragraph, and a button. The background of the circle is a blurred image of a person's face.

 Citizen Science

Share your journey

If you live with the burden of pain, or symptoms of long COVID, consider becoming a citizen scientist today. You can give us useful information. It will help guide health research and improve the lives of people living with similar health challenges.

[I want to participate](#)



Concluding remarks



An empowering approach in advancing health science!

W21

- We believe in science “for the people” and “by the people”!
- An empowering pathway for both **citizens** and **science** built through public participation in health research.
- Citizen engagement in health advances:
 - a) health research;
 - b) health literacy;
 - c) citizen-driven advocacy, and
 - d) interdisciplinarity in health science.



Open questions for discussion

W21

1. [open] Data repercussions

→ Data ethics and privacy concerns?

1. [Personal vs Collective data]

→ Preferences, patient history vs aggregated/massification of data.

1. [GDPR/open science for palliative care]

→ Ownership, disclosure, empowerment



References

1. Wright, M. T., Springett, J., & Kongats, K. (2018). What Is Participatory Health Research? In M. T. Wright & K. Kongats (Eds.), *Participatory Health Research: Voices from Around the World* (pp. 3–15). Springer International Publishing. https://doi.org/10.1007/978-3-319-92177-8_1
2. Marlett, N., Shklarov, S., Marshall, D., Santana, M. J., & Wasylak, T. (2015). Building new roles and relationships in research: A model of patient engagement research. *Quality of Life Research*, 24(5), 1057–1067. <https://doi.org/10.1007/s11136-014-0845-y>
3. Smith, E., Bélisle-Pipon, J.-C., & Resnik, D. (2019). Patients as Research Partners; How to Value their Perceptions, Contribution and Labor? *Citizen Science: Theory and Practice*, 4(1). <https://doi.org/10.5334/cstp.184>
4. Rouleau, G., Bélisle-Pipon, J.-C., Birko, S., Karazivan, P., Fernandez, N., Bilodeau, K., Chao, Y.-S., de Pokomandy, A., Foley, V., Gagnon, B., Gontijo Guerra, S., Khanji, C., Lamoureux-Lamarche, C., Lebouché, B., Lunghi, C., Menear, M., Riverin, B. D., & Rodrigue, C. (2018). Early career researchers' perspectives and roles in patient-oriented research. *Research Involvement and Engagement*, 4(1), 35. <https://doi.org/10.1186/s40900-018-0117-z>
5. 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>

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Open, social learning

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<https://web2learn.eu/>

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