New Approaches to Patient Public Involvement (PPI) in Neurological Research

Maria Teresa Ferretti, Priv Doz, PhD, FEAN
Co-founder and Head of stakeholder Engagement,
Walking the Talk for Dementia

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Faculty Disclosure

	No, nothing to disclose
X	Yes, please specify:

Company Name	*Honorary/ Expenses*	*Consulting/ Advisory Board*	*Funded Research*	*Royalties/Patents*	*Stock Options*	*Ownership/ Equity Position*	*Employee*	*Other (please specify)*
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Syntropic Medical							X	

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	Yes, please specify:

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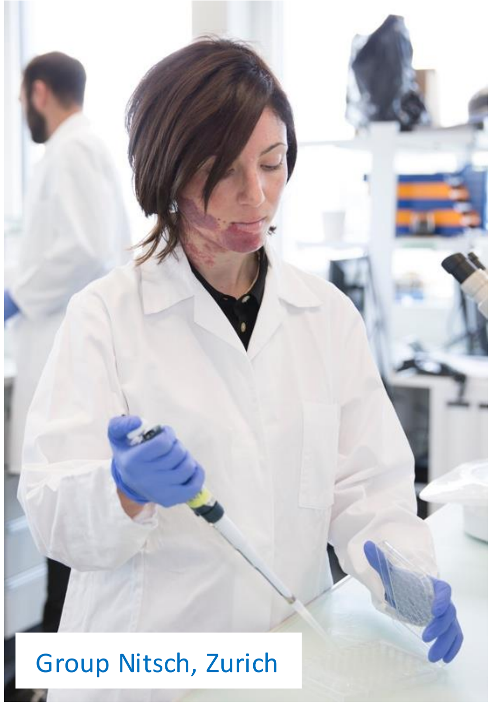
Poll 1

Have you ever heard of Patient and Public Involvement (PPI)?

About me...


Group Nitsch, Zurich


Syntropic Medical, Vienna


With Maya Uccheddu, PWLE


With Sofia Petersson, PLWD


Walking the Talk for Dementia

nature reviews neurology

https://doi.org/10.1038/s41582-024-01047-6

Perspective

Check for updates

Inclusion in neurological research: empowering people living with neurolog

Patient expert

Patient expert

Psychiatrist

Neurologist

Maria Teresa Ferretti[1], Maria Bonaria Uccheddu[2,3], Richelle Flanagan[4], Iracema Leroi[5,6] & Elena Moro[7,8]

Abstract

The value of involving people living with diseases in the research process is increasingly recognized by professional associations and regulatory agencies alike. Patient contributions range from disease prevention and diagnosis to medication planning, and from advocacy

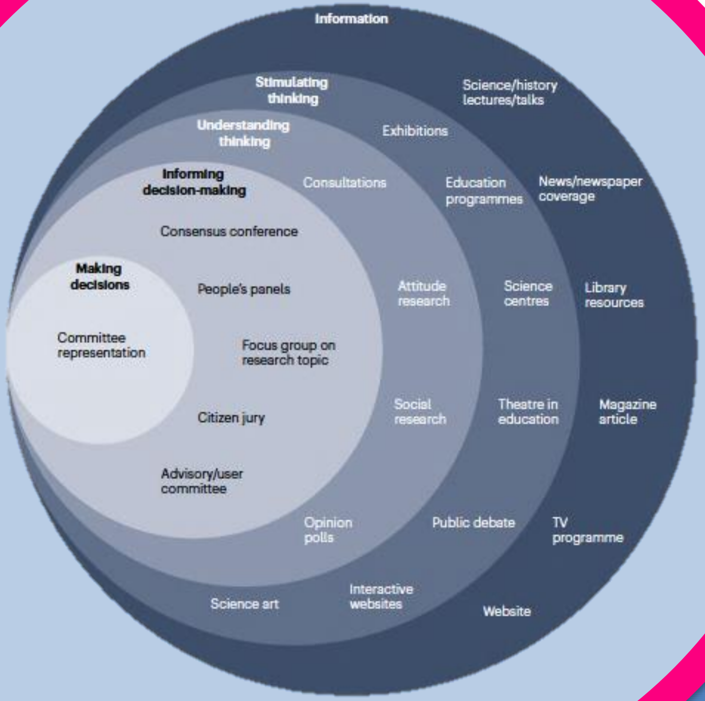
Sections

Questions for today

What is PPI?

Why PPI?

What could you do?

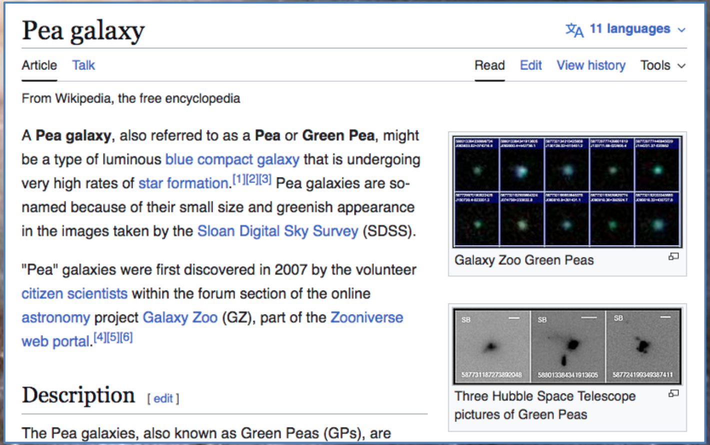

Information
Stimulating thinking
Understanding thinking
Informing decision-making
Making decisions
Science/history lectures/talks
Exhibitions
Consultations
Education programmes
News/newspaper coverage
Consensus conference
People's panels
Attitude research
Science centres
Library resources
Committee representation
Focus group on research topic
Citizen jury
Social research
Theatre in education
Magazine article
Advisory/user committee
Opinion polls
Public debate
TV programme
Science art
Interactive websites
Website

1 . What is PPI

Getting the public closer to science

Citizen science can:

- accelerate discovery
- improve data quality
- open new research questions



Pea galaxy

From Wikipedia, the free encyclopedia

A **Pea galaxy**, also referred to as a **Pea** or **Green Pea**, might be a type of luminous blue compact galaxy that is undergoing very high rates of star formation.[1][2][3] Pea galaxies are so-named because of their small size and greenish appearance in the images taken by the Sloan Digital Sky Survey (SDSS).

"Pea" galaxies were first discovered in 2007 by the volunteer citizen scientists within the forum section of the online astronomy project Galaxy Zoo (GZ), part of the Zooniverse web portal.[4][5][6]

Galaxy Zoo Green Peas

Three Hubble Space Telescope pictures of Green Peas

Description [edit]

The Pea galaxies, also known as Green Peas (GPs), are

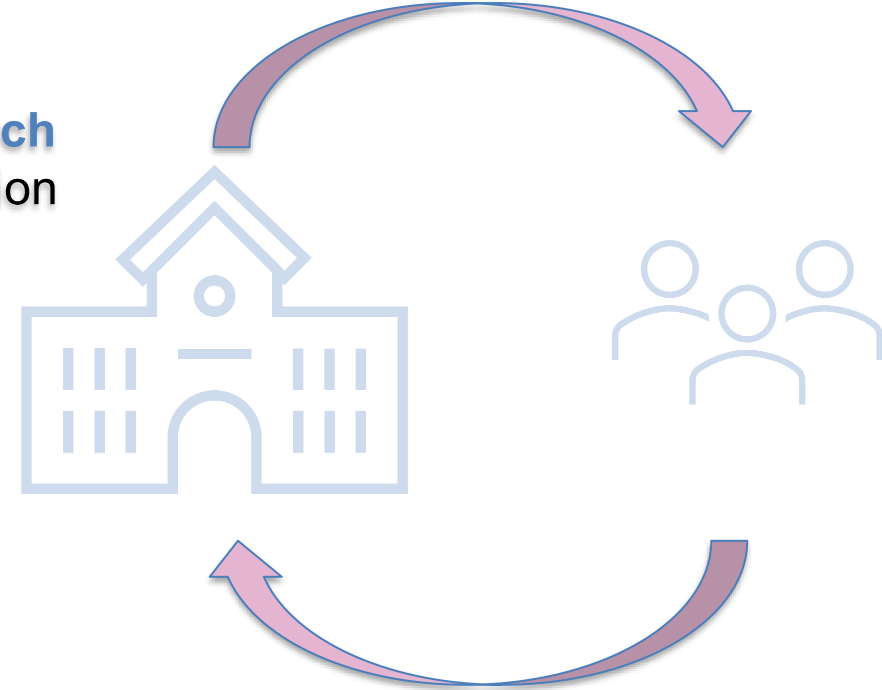
PPI - Patient and public involvement

Patient and public involvement (PPI)
the active and empowered participation of patients/public in processes that affect them, including research.

> “research being carried out **‘with’ or ‘by’** members of the public rather than ‘to’, ‘about’ or ‘for’ them”

https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371

How to integrate PPI in clinical research?



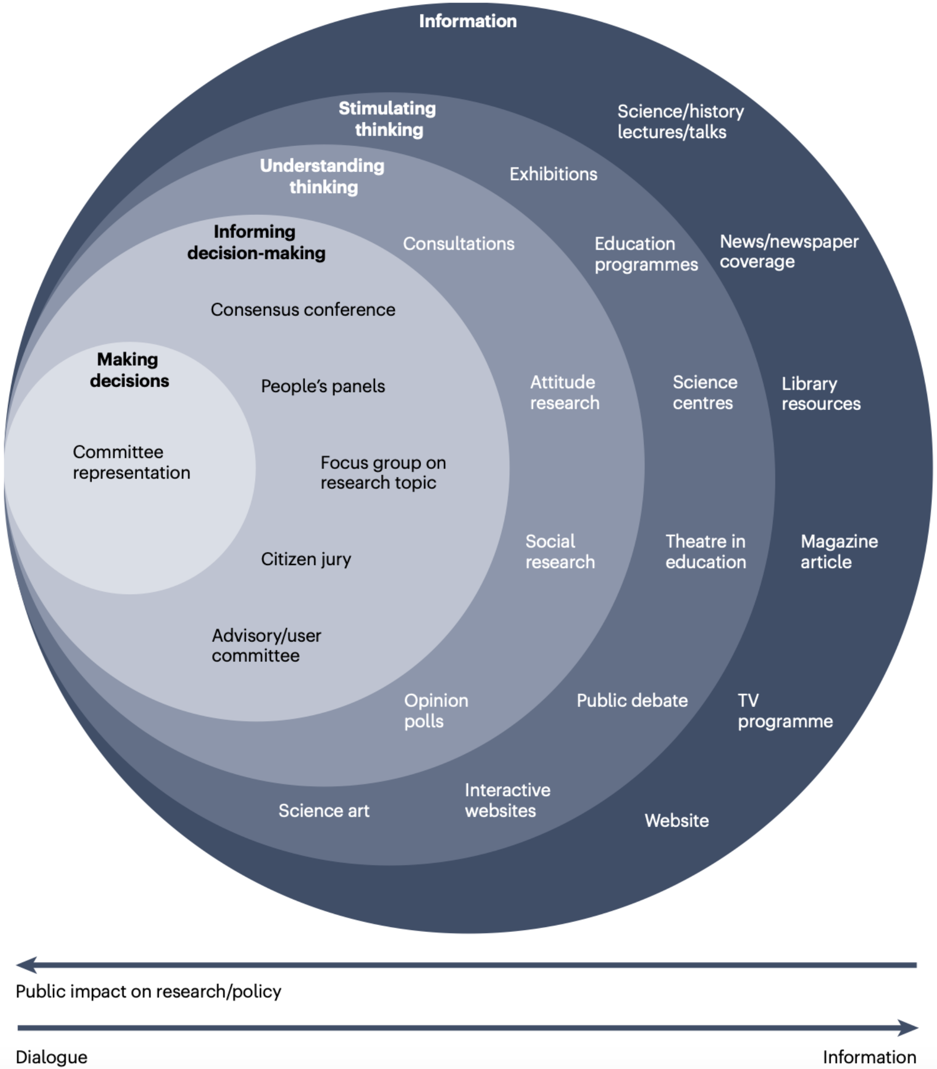
Academic/research

- Conceptualization
- Project writing
- Data analysis
- Publications
- Fundraising
- Clinical trials
- Dissemination

PWLE

- Patients
- Caregivers
- Family members
- Public

PWLE= people with lived experience



Information

Science/history lectures/talks

News/newspaper coverage

Library resources

Magazine article

TV programme

Website

Stimulating thinking

Exhibitions

Education programmes

Science centres

Theatre in education

Public debate

Interactive websites

Science art

Understanding thinking

Consultations

Attitude research

Social research

Opinion polls

Informing decision-making

Consensus conference

People’s panels

Focus group on research topic

Citizen jury

Advisory/user committee

Making decisions

Committee representation

Public impact on research/policy

Dialogue

Information

Modified from Ferretti et al. NRN 2025

PPI can impact research through advocacy

The ice bucket challenge

Measurable effect on ALS research:

- fostering innovative projects
- collaborations and clinical trials
- scientific papers
- catalysed 191% increase in the annual amount of NIH research funding for ALS

Schnell, J. et al. ALS Association Ice Bucket Challenge Impact (RTI International, 2024)

Consultation in grants

[Patients] must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians

Strategy for Patient-Oriented Research - Patient Engagement Framework

https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Poll 2

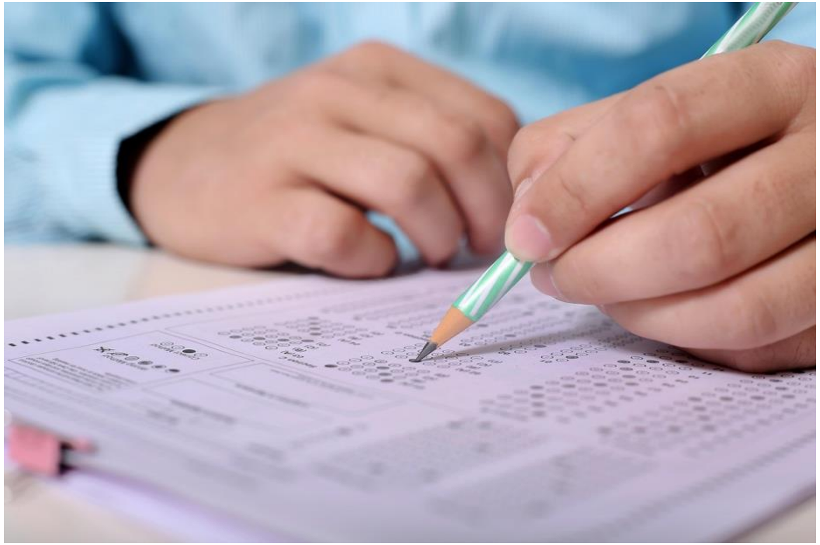
When was the first QoL scale used in clinical research?

Introducing the voice of patients into research - QoL

1948 Karnofsky Performance Scale: the ancestor of quality-of-life indices, filled in by clinicians.

1970s Scales were still written, administered and interpreted by clinicians (largely non-participative PPI)

1980s MRC Daily Diary Card: one of the first quality-of-life assessments designed to be filled in by clinical trial participants, It was used in several MRC cancer treatment studies



Timmermann, C. Chronic Illn. 9, 179–190, (2013)

PPI direct impact on research - PRO

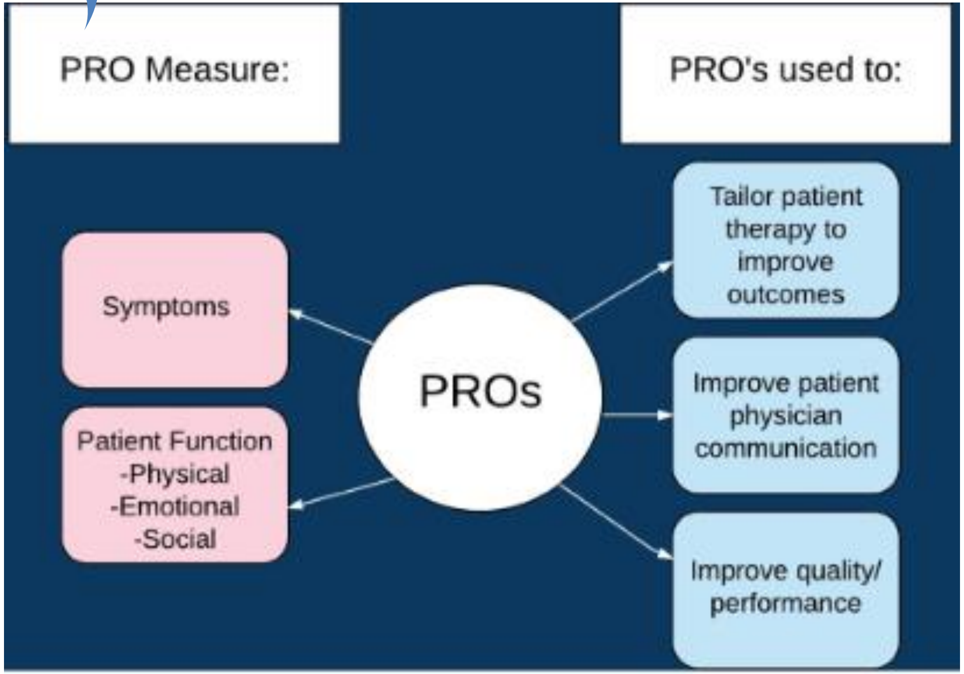
PROs = Patient Reported Outcome

Any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else’

Food and Drug Administration, 2009. [*https://www.fda.gov/downloads/drugs/guidances/ucm193282.pdf*](https://www.fda.gov/downloads/drugs/guidances/ucm193282.pdf)

PRO and PROMS

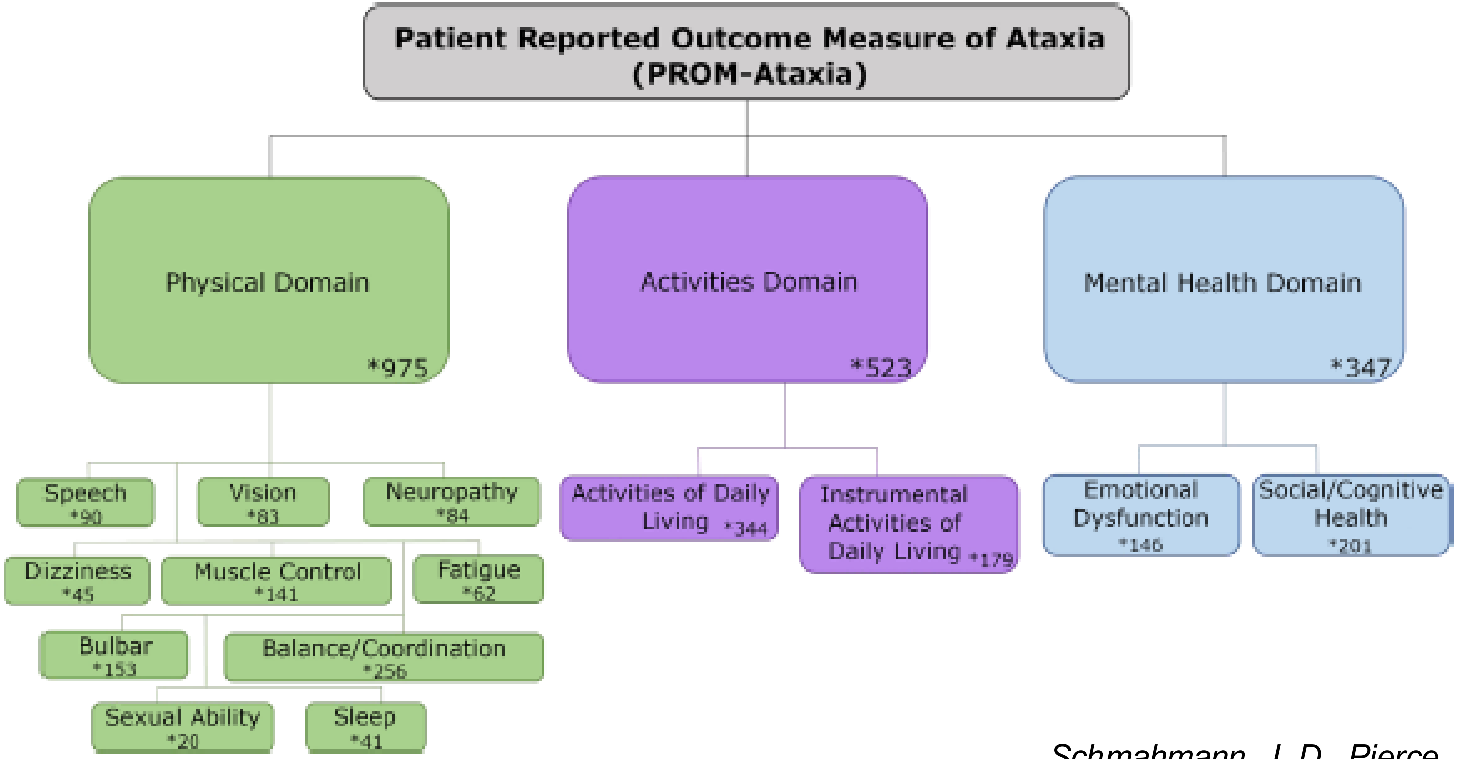
´PRO measures (PROMs) =
self-completed questionnaires



Anderson et al., BMJ 2018

Redefining clinical study outcomes

Example – PRO in ataxia



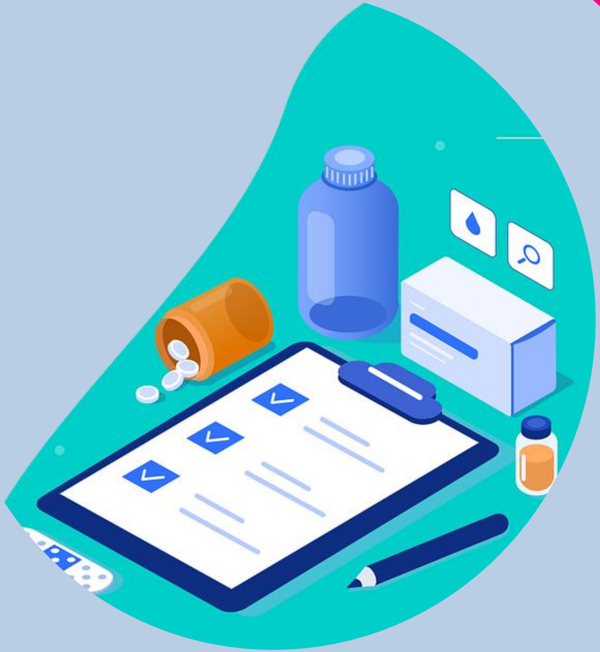
Patient Reported Outcome Measure of Ataxia (PROM-Ataxia)

Physical Domain *975
- Speech *90
- Vision *83
- Neuropathy *84
- Dizziness *45
- Muscle Control *141
- Fatigue *62
- Bulbar *153
- Balance/Coordination *256
- Sexual Ability *20
- Sleep *41

Activities Domain *523
- Activities of Daily Living *344
- Instrumental Activities of Daily Living *179

Mental Health Domain *347
- Emotional Dysfunction *146
- Social/Cognitive Health *201

Schmahmann, J. D., Pierce, S., MacMore, J. & L'Italien, G. J. Mov. Disord. 36, 2367–2377 (2021)



2 . Why PPI?

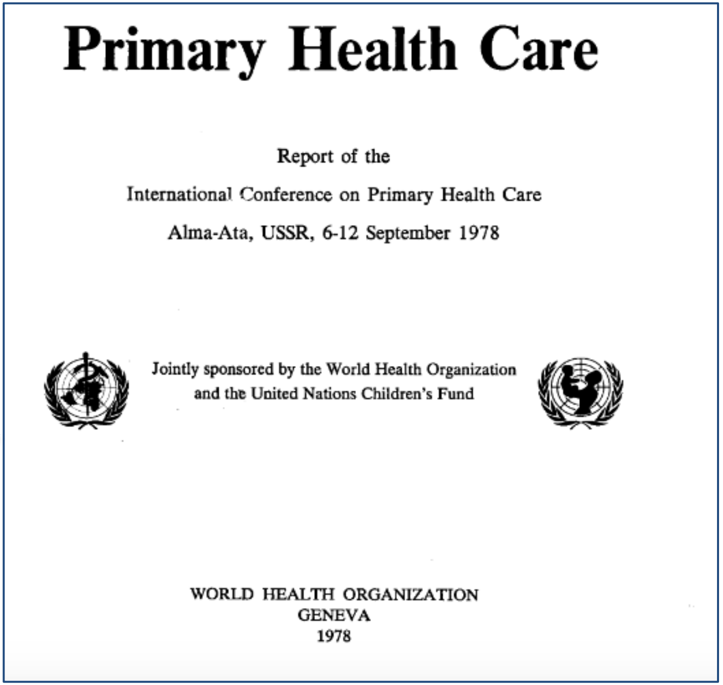
Why PPI?

1. It’s morally and ethically the right thing to do
2. It can improve recruitment and retention
3. It can improve efficiency in a study
4. Regulators want it
5. It can bring to new insights

The ethical point

The involvement of people living with disease in medical research can be seen as a specific case within the larger framework of **public participation in democratic processes**

1978 WHO Alma-Ata declaration: "people have a right and duty to participate individually and collectively in **the planning and implementation of their health care**"



Primary Health Care

Report of the
International Conference on Primary Health Care
Alma-Ata, USSR, 6-12 September 1978

Jointly sponsored by the World Health Organization
and the United Nations Children's Fund

WORLD HEALTH ORGANIZATION
GENEVA
1978

JUST 1% OF PEOPLE

who could take part in clinical trials for dementia do so.

ALZHEIMER'S RESEARCH UK
FOR A CURE

PPI improves recruitment

Example: Cognitive Occupation-Based programme for people with MS (COB-MS) trial (ISRCTN11462710)

Robert Joyce,
Embedded Patient Researcher

Including a researcher with lived experience of MS **substantially enhanced recruitment** efforts for this trial.

-> This personal connection fostered **trust**, as potential participants saw someone who truly understood their journey advocating for the study.

-> The story of the researcher, which was shared through **interviews** and media, resonated deeply with patients, thereby accelerating recruitment and enabling the trial to advance quickly

Joyce, R., Dwyer, C. P. & Hynes, S. M. HRB Open. Res. 4, 11 (2021)

PPI and study efficiency

- Improvement of patient **information sheets**
- Ensuring that research procedures are **acceptable** to participants
- Increasing participant enrolment and **retention**
- Development of research findings that are **applicable** to the patient experience

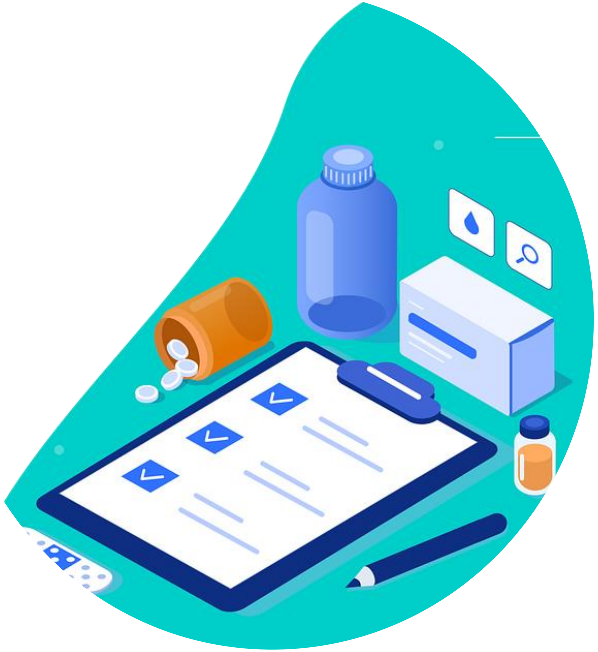
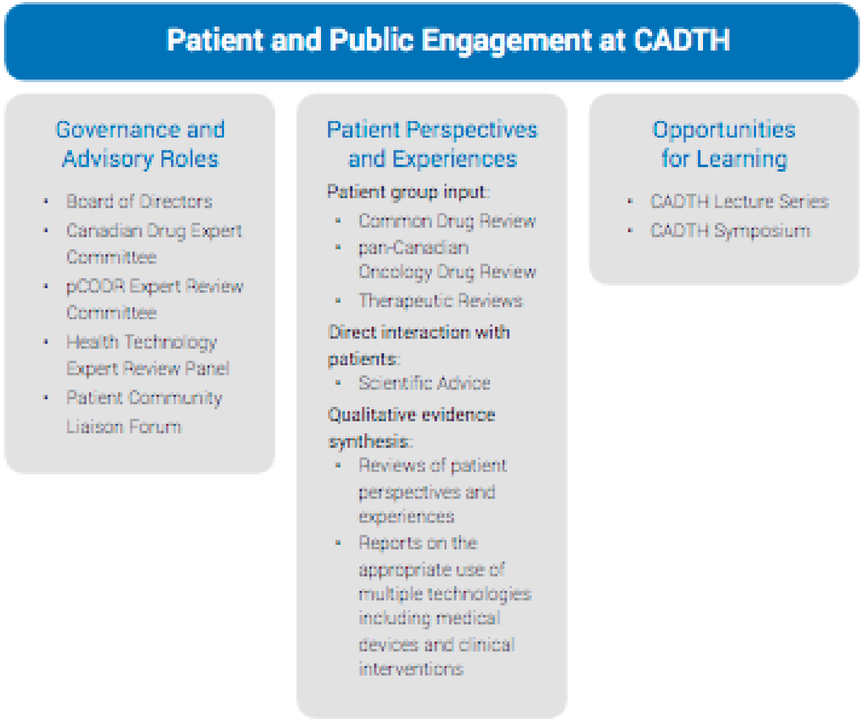


Image by Megan Rexazin Conde from Pixabay

-> Less protocol amendments, quicker completion, lower costs, higher efficacy

PPI and regulators /HTA



Patient and Public Engagement at CADTH

Governance and Advisory Roles

- Board of Directors
- Canadian Drug Expert Committee
- pCODR Expert Review Committee
- Health Technology Expert Review Panel
- Patient Community Liaison Forum

Patient Perspectives and Experiences

Patient group input:

- Common Drug Review
- pan-Canadian Oncology Drug Review
- Therapeutic Reviews

Direct interaction with patients:

- Scientific Advice

Qualitative evidence synthesis:

- Reviews of patient perspectives and experiences
- Reports on the appropriate use of multiple technologies including medical devices and clinical interventions

Opportunities for Learning

- CADTH Lecture Series
- CADTH Symposium

https://www.eu-patient.eu; https://www.cda-amc.ca/sites/default/file

Patient-led research is powerful and insightful

Tech boss uses AI and ChatGPT to create cancer vaccine for his dying dog

The tale of this heartbroken tech entrepreneur, his tumour-riddled rescue dog and a cure for cancer has leading scientists astounded.

3. What you could do

Actions for you:

1. Promote patient training
2. Consider involving people with lived experience (PWLE)
3. Educate yourself on PPI

1. Promote patient training

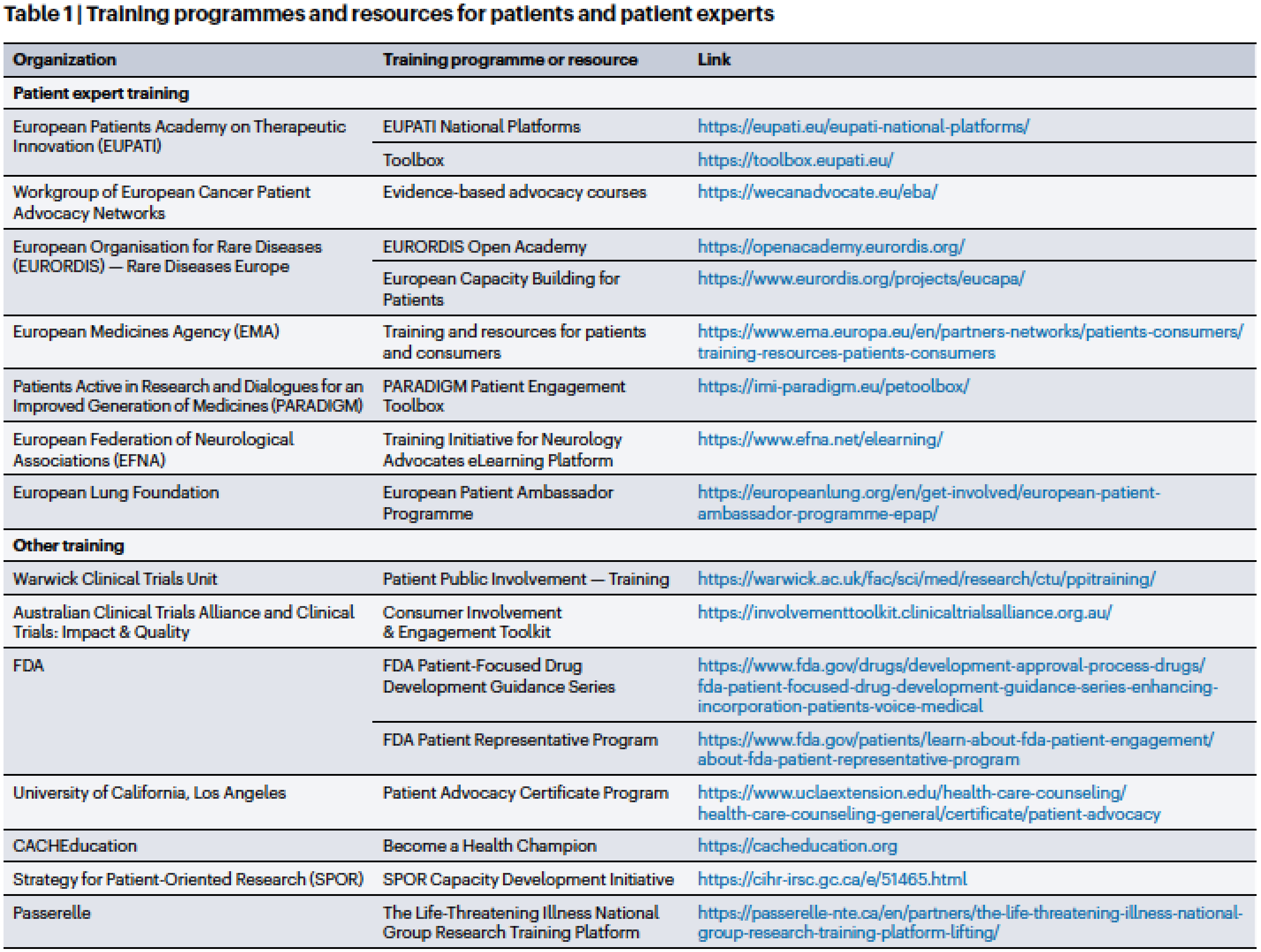


Table 1 | Training programmes and resources for patients and patient experts

Organization	Training programme or resource	Link
Patient expert training		
European Patients Academy on Therapeutic Innovation (EUPATI)	EUPATI National Platforms	https://eupati.eu/eupati-national-platforms/
	Toolbox	https://toolbox.eupati.eu/
Workgroup of European Cancer Patient Advocacy Networks	Evidence-based advocacy courses	https://wecanadvocate.eu/eba/
European Organisation for Rare Diseases (EURORDIS) — Rare Diseases Europe	EURORDIS Open Academy	https://openacademy.eurordis.org/
	European Capacity Building for Patients	https://www.eurordis.org/projects/eucapa/
European Medicines Agency (EMA)	Training and resources for patients and consumers	https://www.ema.europa.eu/en/partners-networks/patients-consumers/training-resources-patients-consumers
Patients Active in Research and Dialogues for an Improved Generation of Medicines (PARADIGM)	PARADIGM Patient Engagement Toolbox	https://imi-paradigm.eu/petoolbox/
European Federation of Neurological Associations (EFNA)	Training Initiative for Neurology Advocates eLearning Platform	https://www.efna.net/elearning/
European Lung Foundation	European Patient Ambassador Programme	https://europeanlung.org/en/get-involved/european-patient-ambassador-programme-epap/
Other training		
Warwick Clinical Trials Unit	Patient Public Involvement — Training	https://warwick.ac.uk/fac/sci/med/research/ctu/ppitraining/
Australian Clinical Trials Alliance and Clinical Trials: Impact & Quality	Consumer Involvement & Engagement Toolkit	https://involvementtoolkit.clinicaltrialsalliance.org.au/
FDA	FDA Patient-Focused Drug Development Guidance Series	https://www.fda.gov/drugs/development-approval-process-drugs/fda-patient-focused-drug-development-guidance-series-enhancing-incorporation-patients-voice-medical
	FDA Patient Representative Program	https://www.fda.gov/patients/learn-about-fda-patient-engagement/about-fda-patient-representative-program
University of California, Los Angeles	Patient Advocacy Certificate Program	https://www.uclaextension.edu/health-care-counseling/health-care-counseling-general/certificate/patient-advocacy
CACHEducation	Become a Health Champion	https://cacheducation.org
Strategy for Patient-Oriented Research (SPOR)	SPOR Capacity Development Initiative	https://cihr-irsc.gc.ca/e/51465.html
Passerelle	The Life-Threatening Illness National Group Research Training Platform	https://passerelle-nte.ca/en/partners/the-life-threatening-illness-national-group-research-training-platform-lifting/

2. Consider involving PWLE

MCI patients, people with early dementia stages and caregivers are eager to learn and help

- Embedded researchers
- Educational activities/clinical updates in trials
- Meet ups between researchers and PWLE

Walking the Talk for Dementia

3. Further educate yourself on PPI

Patient Engagement
RESOURCE CENTRE

Patients should be involved in your research

We are here to help you get started.

https://patient-engagement.eu/

Resources

Journals:
Nature Reviews Neurology series World View:
https://www.nature.com/nrneurol/articles?type=world-view

PPI organizations:
EUPATI https://eupati.eu/
Patient Engagement https://patient-engagement.eu/
Admedicum: https://admedicum.com/why-patient-engagement-matters/
Eurordis: https://download2.eurordis.org/ern/Patient-Partnership-Framework/2023/PPF.pdf

Individual patient experts:
Sarah Riggare
Robert Joyce
Richelle Flanagan
Maya Uccheddu
Rachel Wurzman
Jon Nelson

Summary

PPI in medical research belongs to public participation in democratic processes

PPI in clinical research has been shown to improve recruitment, retention, and overall efficiency of studies

Consider actively involving PWLE who are interested in helping – resources are available

Poll 3

Will you consider in the future integrating PPI in your work?

To contact me:

Mariateresa.ferretti@gmail.com
https://www.linkedin.com/in/maria-teresa-ferretti-241849115/

Thanks!