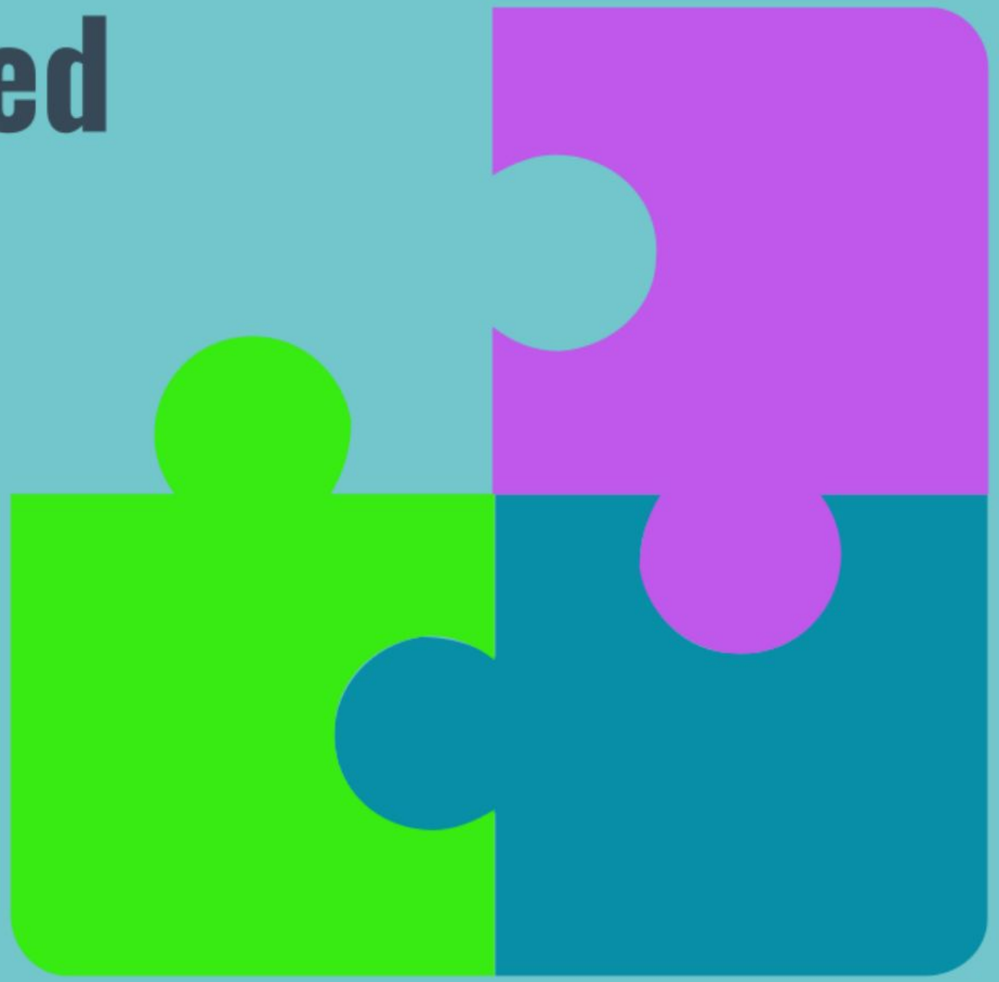
The power of human lived experience in a virtual human world



Virtual Human Global Summit II

October 23–24, 2025

Steve Bourke BSc.MPhil. MSc. EUPATI Fellow

What are the words you use when you think of you being or about patients in real or virtual world?

21 7 3 14 2 53

What are the types of patients?

21 7 3 14 2 37

Our perception of patients

"Every experience you have with the world enters your brain through sensation, through your sensory organs, like your eyes and your ears, but your sensations integrate with what's already in your mind, what you're already thinking, what you already believe."

How memories shape your reality | TEDX New England

Dr. Aleena Garner Sep 12, 2025

#PeopleWhoArePatients

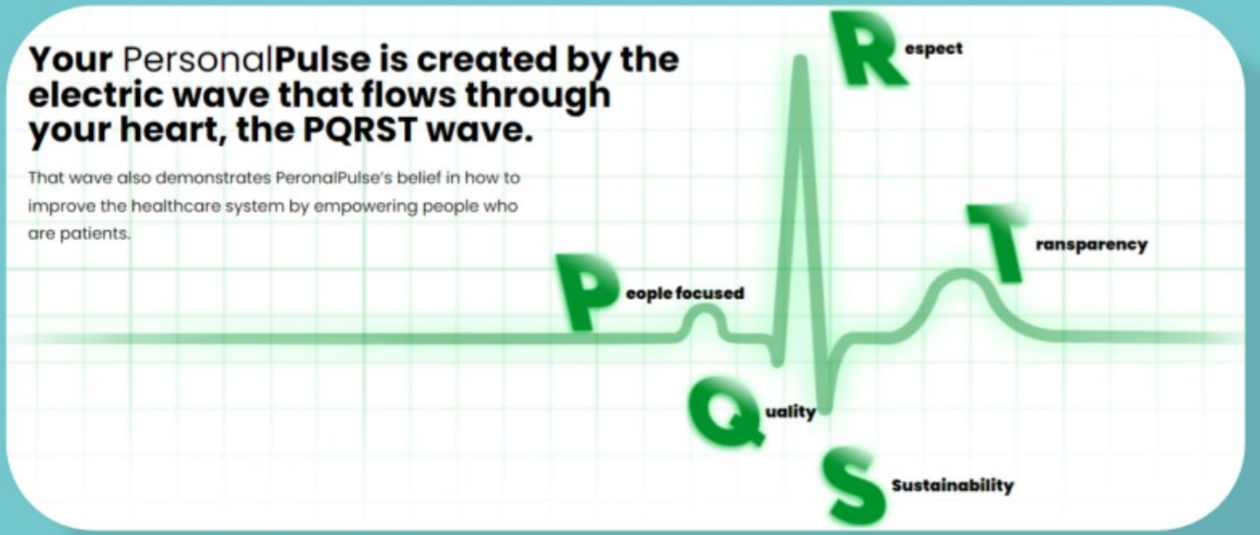
Patient Partners

- Patient organisations
- Patient groups
- Caregivers
- Family members
- Individual patients
- Patient associations
- Patient advocacy groups
- Patient communities
- Patient experts
- Online patient communities

My Experience and my experience

Your PersonalPulse is created by the electric wave that flows through your heart, the PQRST wave.

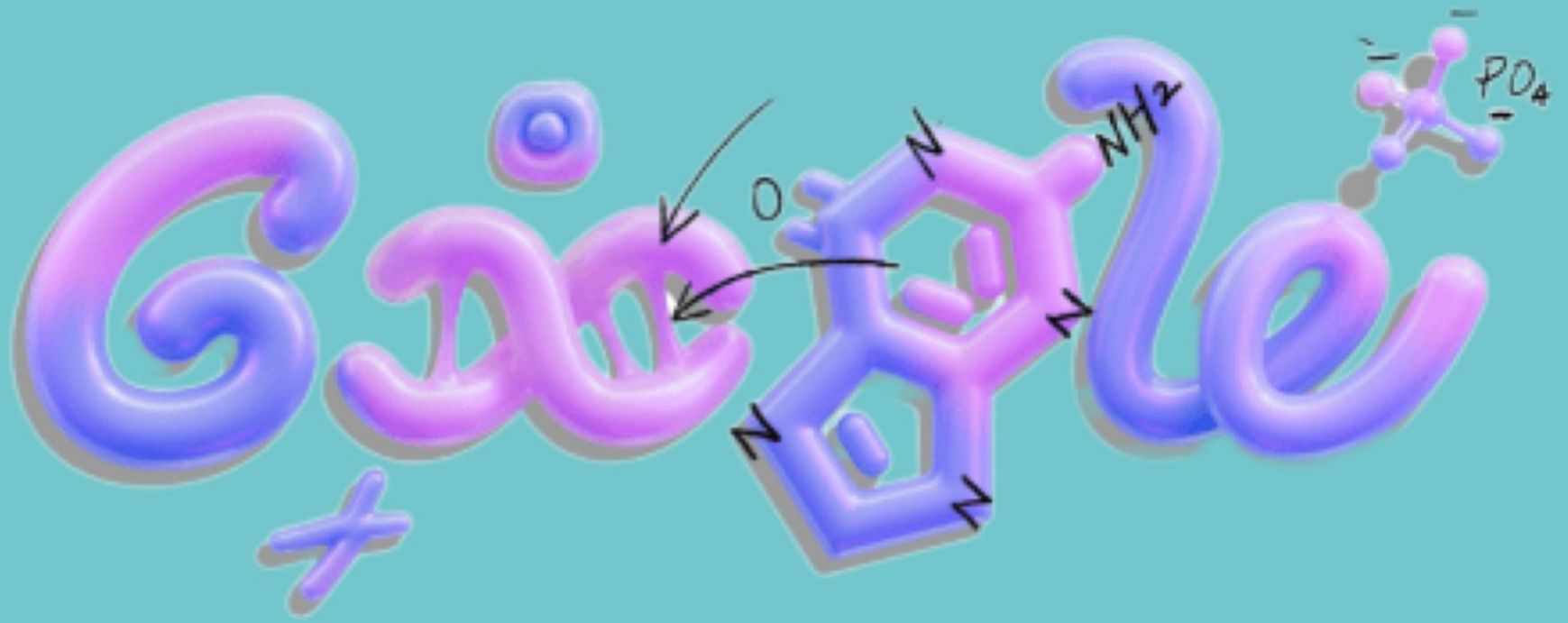
That wave also demonstrates PeronalPulse's belief in how to improve the healthcare system by empowering people who are patients.



EUPATI SWITZERLAND
European Patients' Academy on Therapeutic Innovation

Personal PULSE
EMPOWERING PEOPLE WHO ARE PATIENTS

Personalised? Global? Equitable?



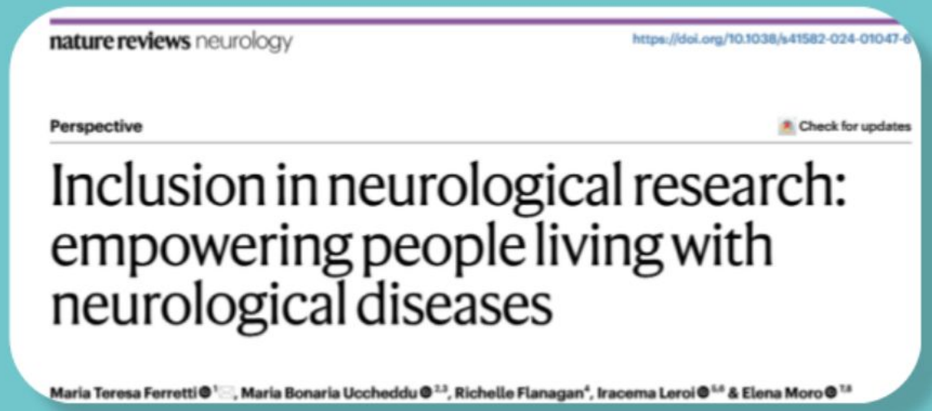
Assumption makes a fool of you and I

Stand up if you support People who are Patients

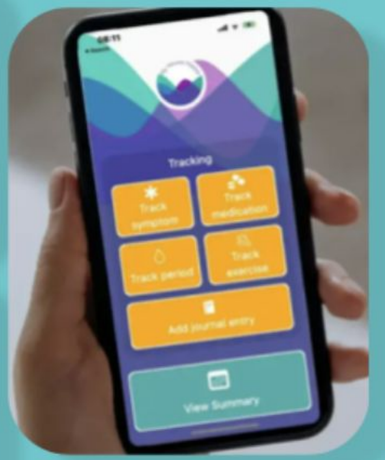
Stay standing if you have used patients data

Stay standing if you discussed with the community in advance

Patient experts: Richelle Flanagan

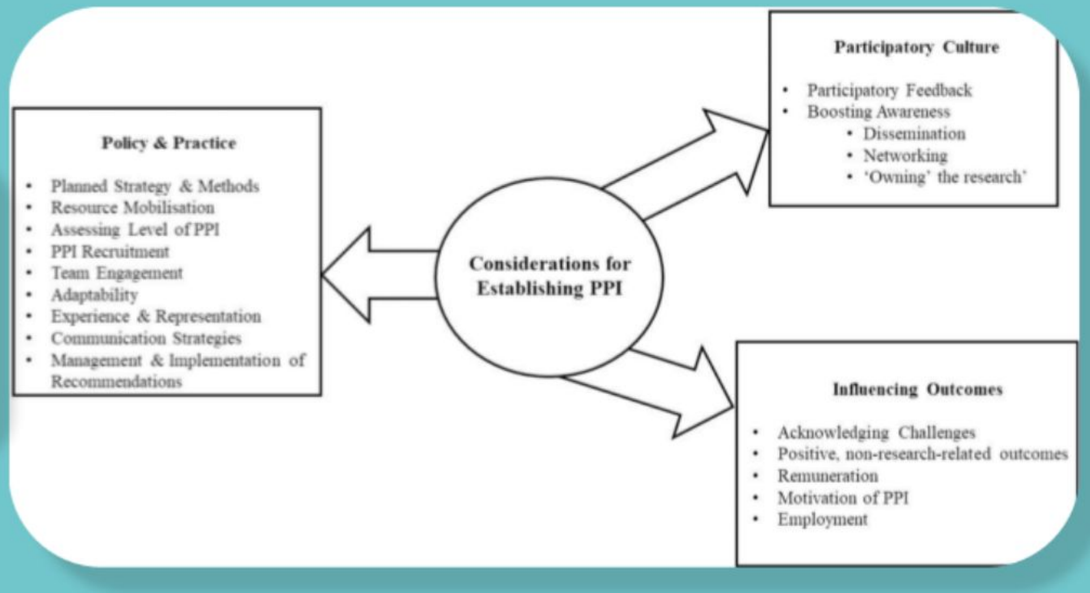


Looking at the impact of different hormonal stages of life of women and their impact on Parkinson's symptoms.

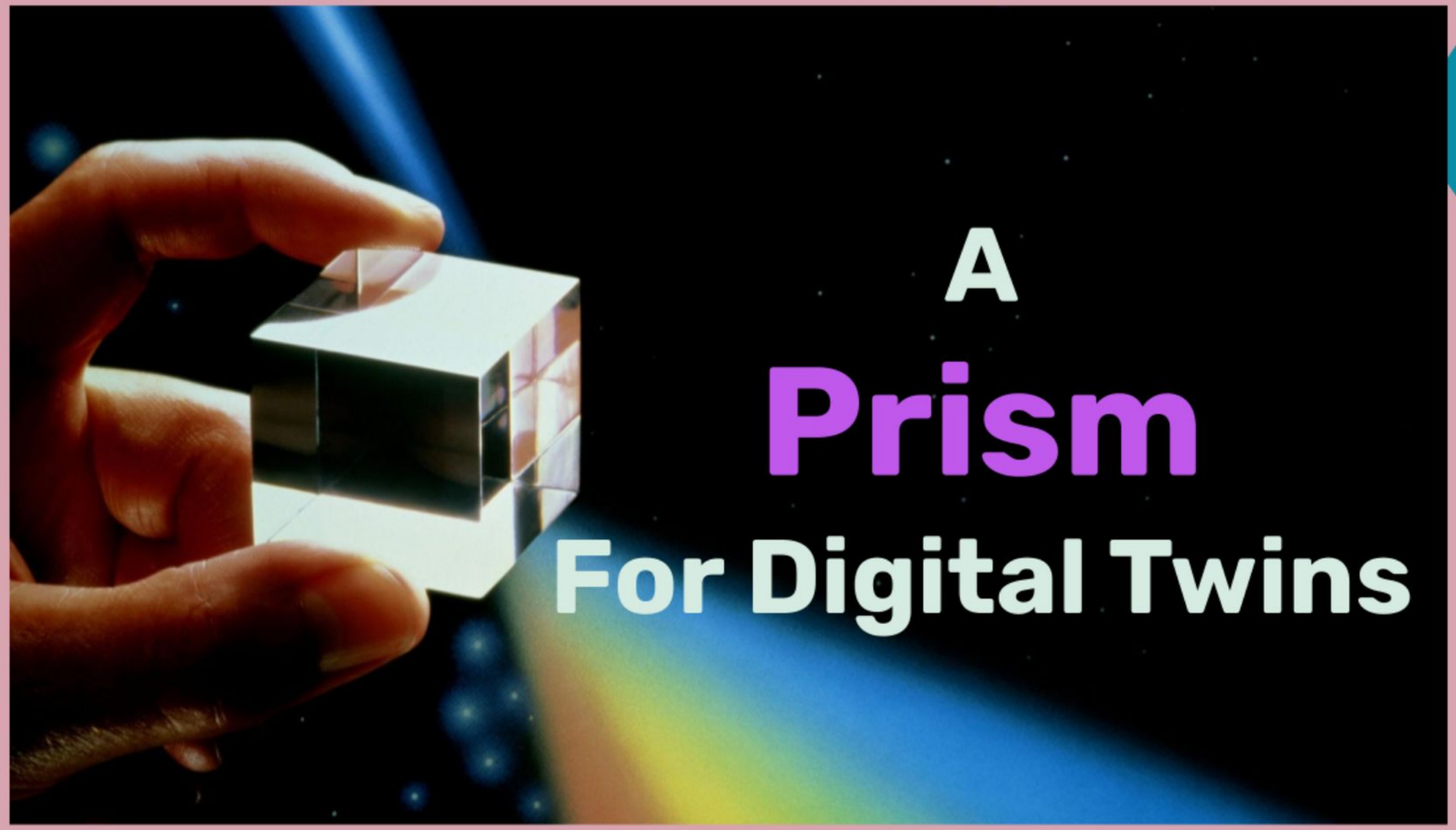


My Moves Matter

Patient experts: Robert Joyce (Embedded patient researcher)



Lived experience



Lived experience Prism

Patient-Generated Health Data -Wearables, apps, self-tracking
Poor interoperability, privacy, unstructured formats

Narrative/Unstructured Data -Stories, interviews, feedback
Hard to analyze, ethical sensitivities, lack of standards

Contextual data -Daily life conditions, social media, local data
Data fragmentation, privacy, non-clinical nature

Lived experience Prism

Digital twins ≠ true digital selves.

Without lived experience data, twins simulate biology but not biography — they lack situated realism.

Dark data → Missing dimensions of humanity.

Each dark data domain represents a dimension of life (daily behavior, felt experience, and context) that digital twins currently fail to capture.

Unlocking potential:

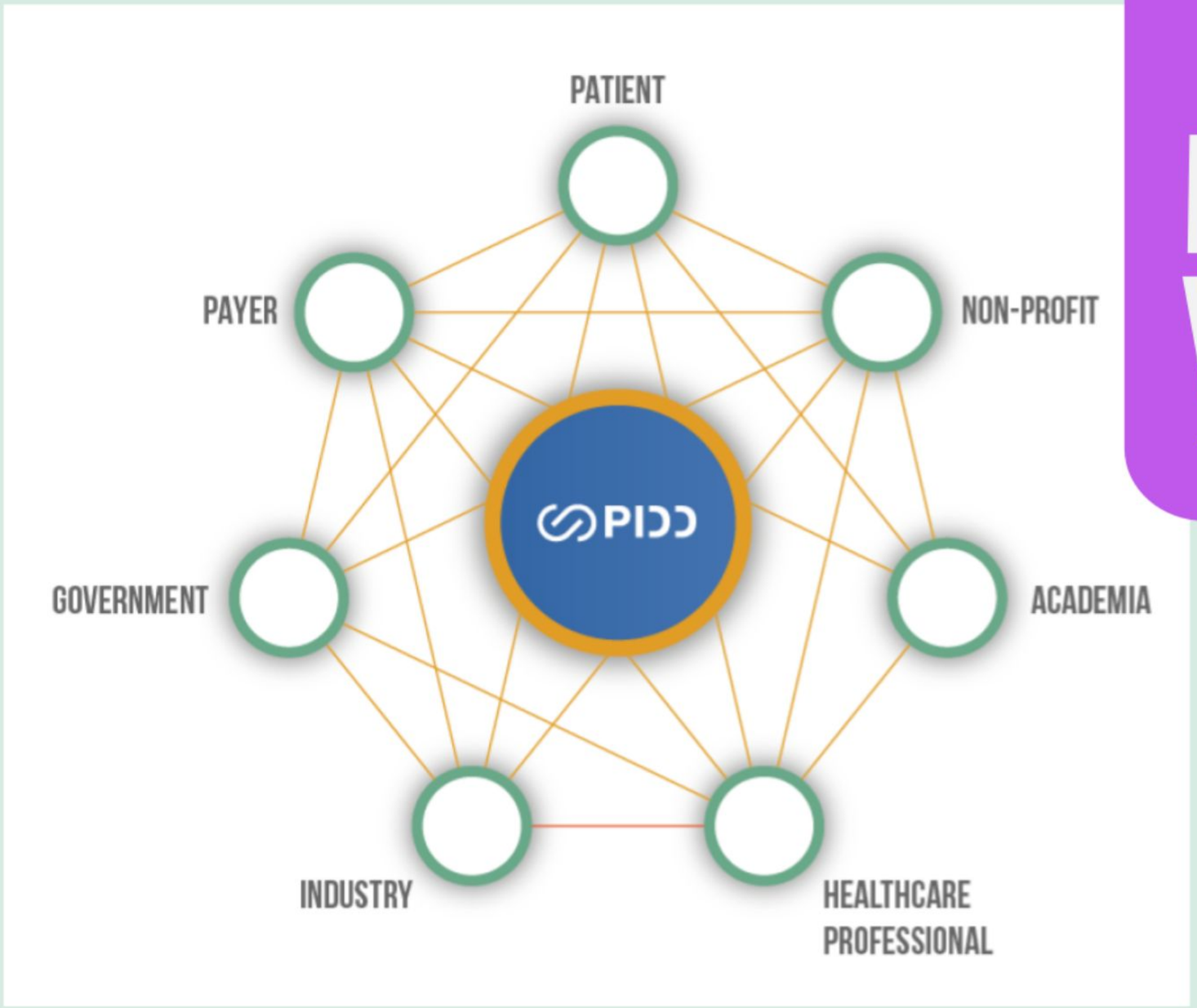
Integrating these “Prism Data” lived experience datasets could move digital twins from clinical avatars toward whole-person models, supporting predictive, preventive, and equitable health systems.

"The power of public and patient involvement in healthcare innovation"

- Patients' individual and community roles
- Patients as co-creators
- Mutual value
- Value measurement
- Positive impact of patient involvement
- Resources for inclusion of the public and patients

21 7 3 14 2

Mutual Value



VALUE POINTS

- Solution developed and designed with patients for patients
- An outcome that addresses unmet needs is a solution that is better accepted
- Understanding, not assumptions (outside-in approach instead of inside-out)
- The mindset of mutual value “From We to Us”
- Advancing a long term sustainable patient community support beyond the clinical

Actions to impact

Table 1 | 'Dos and don'ts' in public patient involvement

Do	Don't
Look to commit to a sustainable equal partnership for the long-term	Do not begin conversations with a mindset of 'this is what we need' (move from 'we' to 'us')
Choose the person(s) representing your organization with care, on the basis of knowledge and soft skills; aim to have a single point of contact who is there for the long term	Do not assume that jargon and acronyms are understood or have the same meaning (look to have common language agreement)
Address possible conflicts of interest by respecting the independence and integrity of individuals and organizations	Do not forget to contact communities at the same time or in advance of press releases (coordinate media engagement)
Start small and let the relationship evolve, while agreeing together on an exit and maintenance strategy	Do not neglect to be inclusive of a diverse range of experience and insights
Ensure expectations, goals and desired outcomes (short and long term) are defined and agreed; give it time and do not expect instant results	Do not make decisions in a vacuum without aligning with colleagues from a range of functions
Seek out alternative resource exchange in addition to monetary resources, such as expert knowledge, mentorship, access to resources, co-authorship and co-application for funding opportunities	Do not expect communities to adjust to your needs as a result of financial commitment
Create a relationship that can evolve into a partnership that is built on mutual values and respect as well as shared interests	Do not seek to influence a community strategy to align with the needs of a business or research question
Look to use and expand the current patient and public involvement materials	Do not assume that guidance created with one community or for one technology will be a fit for other communities; if in doubt ask the community

Action Items

Integrate: Make patient-defined value a core input in Digital Twin projects.

Invest: Fund advocacy groups to generate and gain insights from lived experience data .

Incentivize: Create models that reward long-term sustainable patient community involvement not just short-term procedural success.

THANK YOU!

Steve Bourke MPhil. MSc. EUAPTI Fellow
Email: steve@personalpulse.com
Phone: +41 79 961 13 36
LinkedIn:www.linkedin.com/in/personalpulsestevebourke/
Website: www.personalpulse.com