ISPOR 2025

From System-Centric To Patient-Centric

How Can We Incorporate Patient Centricity Into Real World Evidence Used for Decision-Making?

Fast Facts Session
May 14, 2025

Who we are

Evelyn Pyper

Health Data Strategy Lead,
Roche Canada

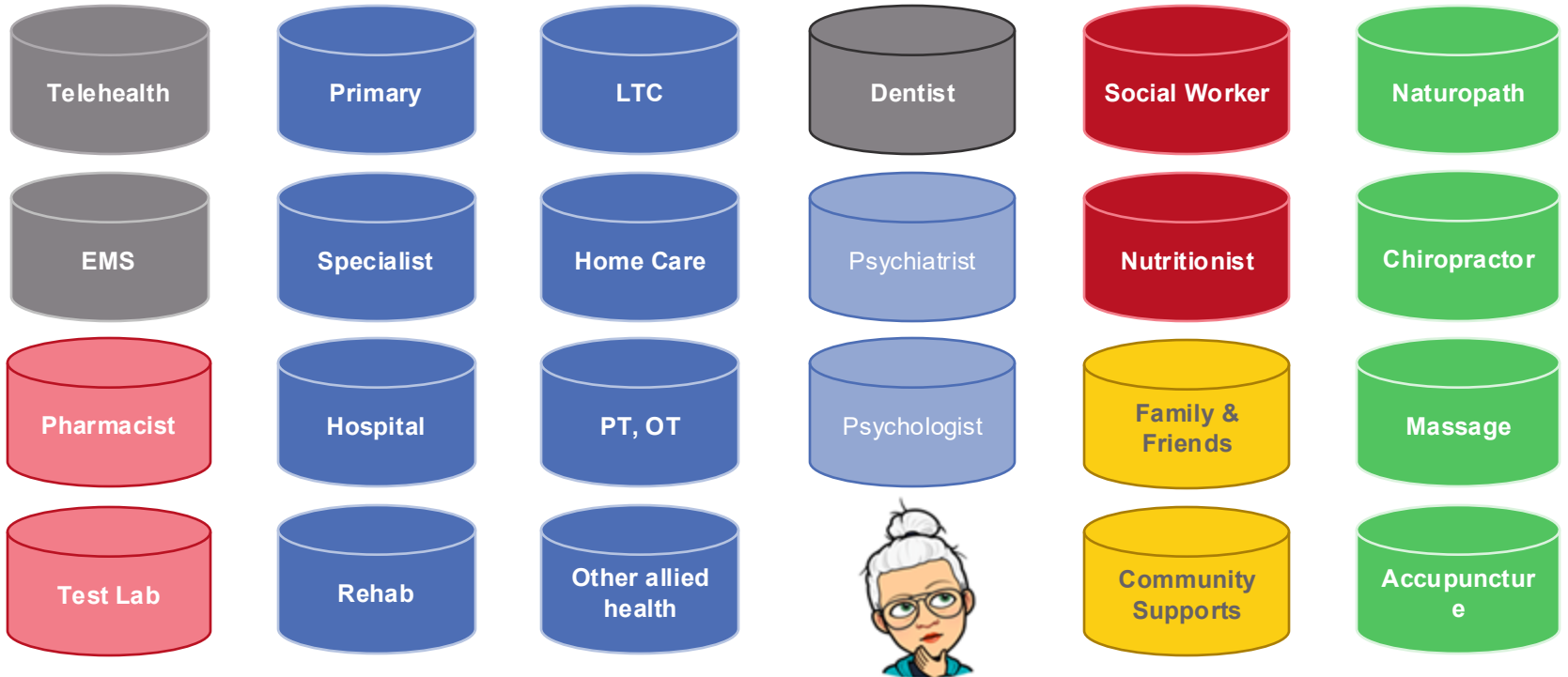**Alies Maybee**
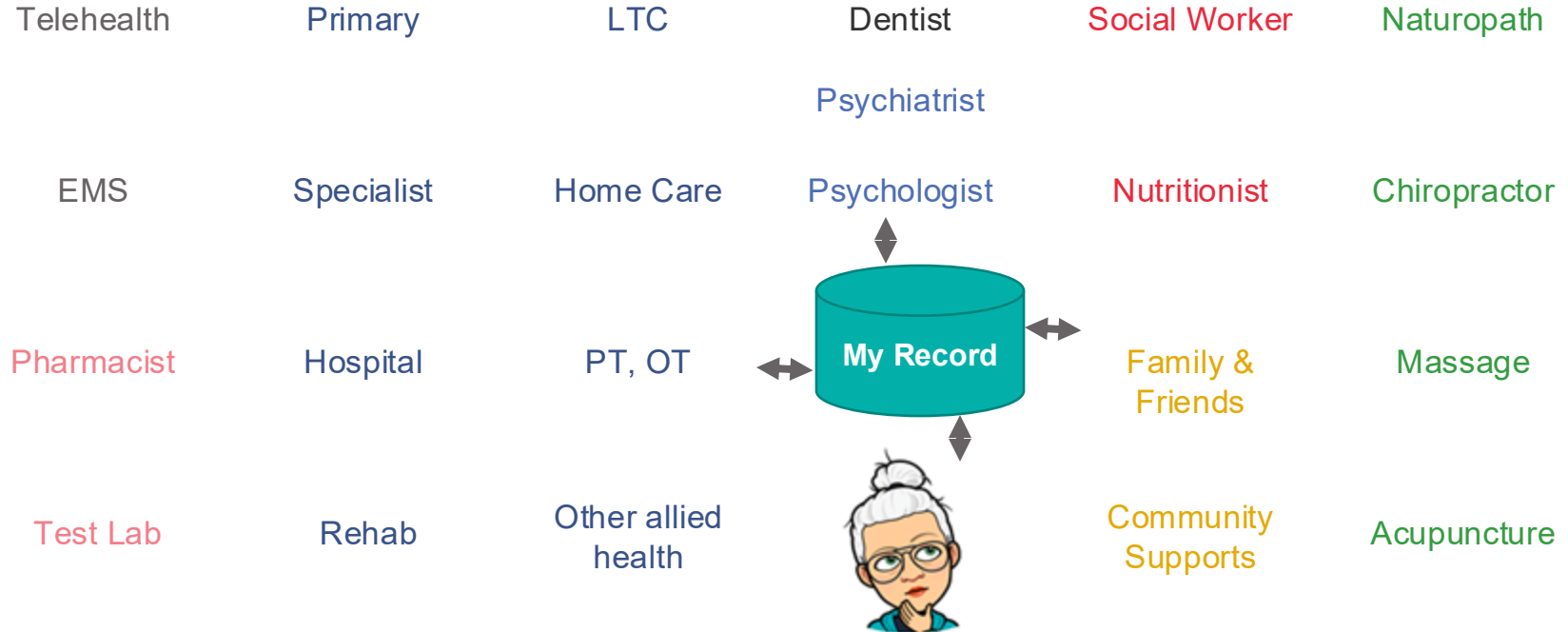
Patient Partner & Co-Chair,
Patient Advisors Network

No conflicts of interest to declare

Without Data There is No Public Health

Without Data There

There is No Public Health

Without Data There is No Health

No Artificial Intelligence

Without Data There is No Population Hea

al Care

Without Data There is No Population Health

Without Data There is No Public Health

tion Health

Without Data There is No Health Resear

ta There is No Health Innovation

Without Data There is No V

Without Data There is No Health Care

ut Data There is No Artificial Intelligence

Without Data There

telligence

Without Data There is No Health Innova

No Virtual Care

Without Data There is No Population Health

Without D

a There is No Artificial Intelligence

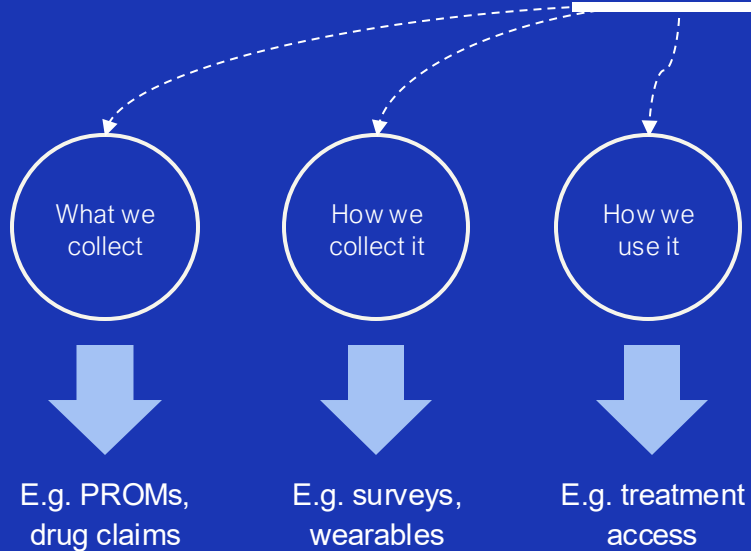Without Data There is No Health Innov
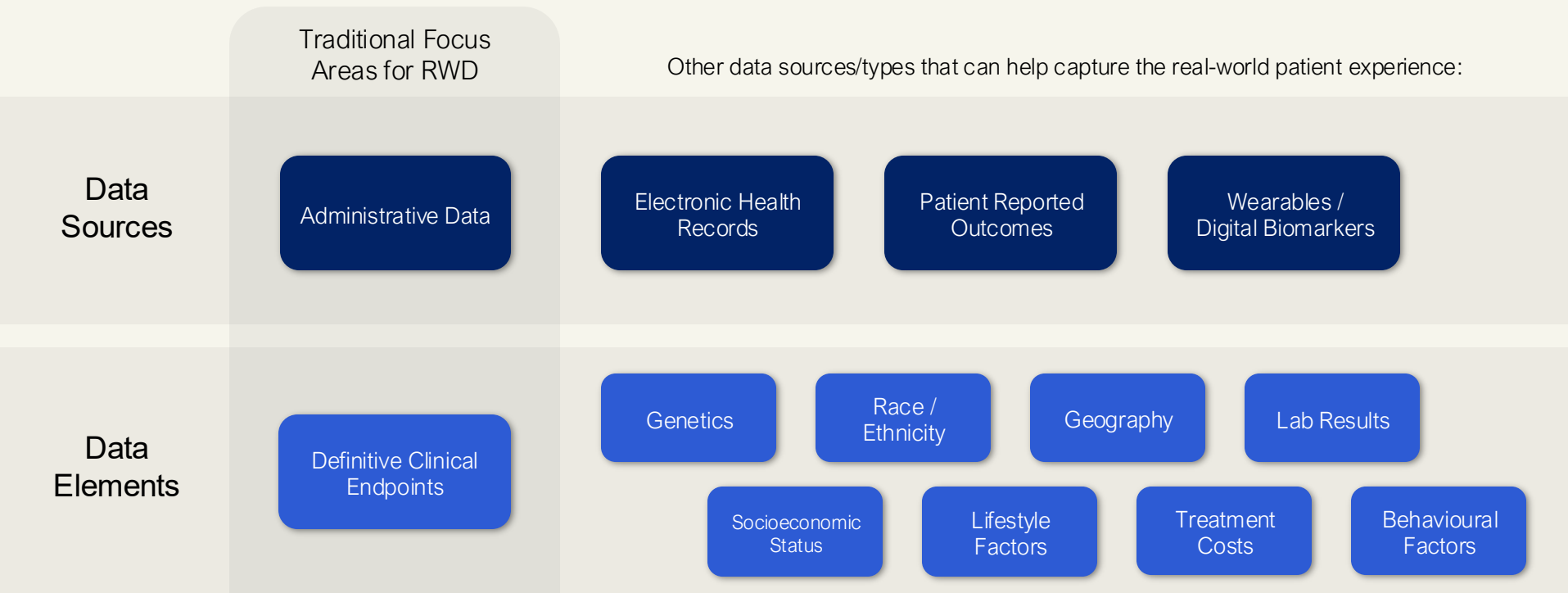
Who treats me? Where is my data?

What we want: one person = one record

Telehealth   Primary   LTC   Dentist   Social Worker   Naturopath

                                          Psychiatrist

EMS   Specialist   Home Care   Psychologist   Nutritionist   Chiropractor

Pharmacist   Hospital   PT, OT   **My Record**   Family &   Massage
                                                             Friends

Test Lab   Rehab   Other allied   Community   Acupuncture
                               health   Supports

Patient-centricity in the context of data

What we collect

How we collect it

How we use it

E.g. PROMs, drug claims

E.g. surveys, wearables

E.g. treatment access

Consider the diverse types of RWD sources and elements that exist

	Traditional Focus Areas for RWD	Other data sources/types that can help capture the real-world patient experience:		
Data Sources	Administrative Data	Electronic Health Records	Patient Reported Outcomes	Wearables / Digital Biomarkers
Data Elements	Definitive Clinical Endpoints	Genetics / Race / Ethnicity / Geography / Lab Results / Socioeconomic Status / Lifestyle Factors / Treatment Costs / Behavioural Factors		

What might we miss by not including data from patients themselves?
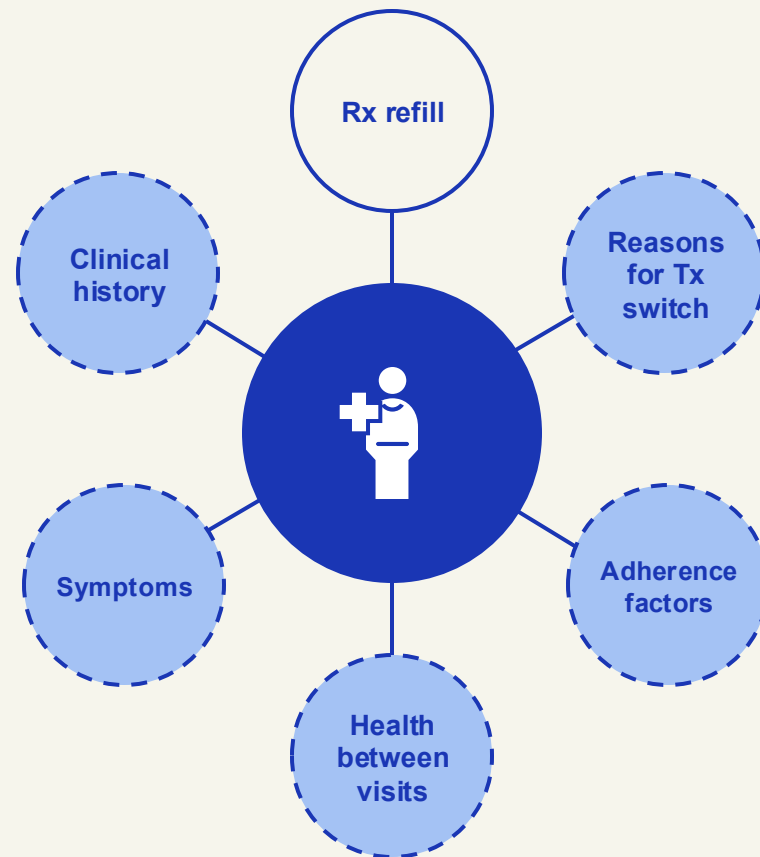
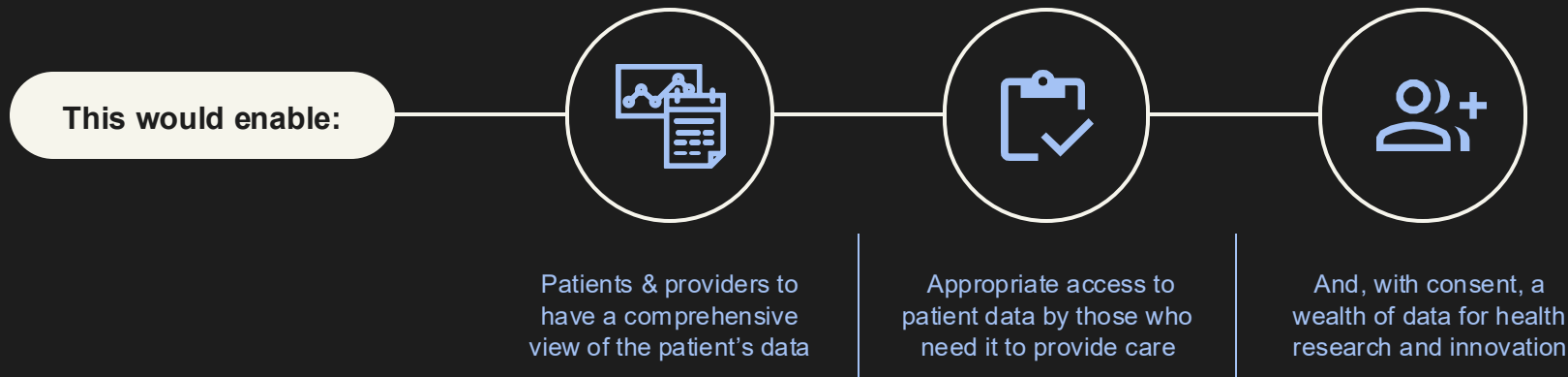# Person-Generated Health Data (PGHD)

Active Data Collection

E.g. Surveys to collect patient-reported outcomes or experience measures (PROMs, PREMs)

Passive Data Collection

E.g. Wearables and other monitors (can be prescribed by clinicians or chosen by individuals)

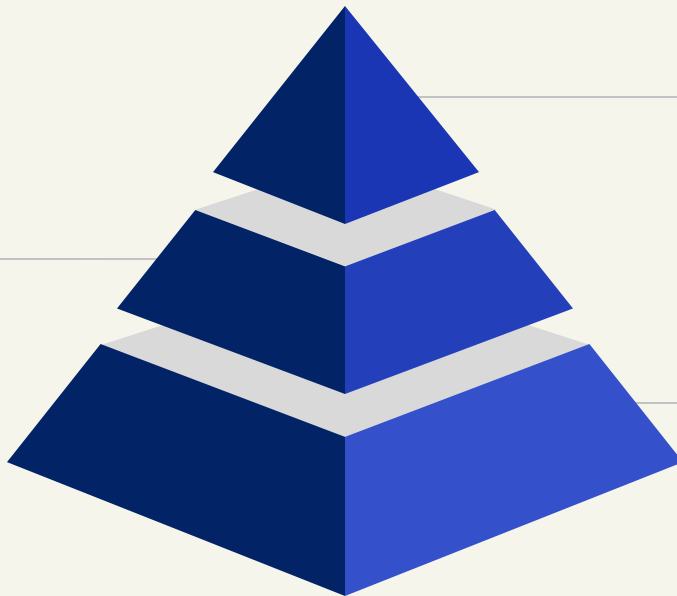# To be truly person-centred, **we need a person-centric health data system.**

This would enable:

Patients & providers to have a comprehensive view of the patient's data

Appropriate access to patient data by those who need it to provide care

And, with consent, a wealth of data for health research and innovation

How do we get to person centricity?

Top-down push for a person-centred data system

1 We need the underlying systems – our plumbing – to mirror our values and approach to care.

Improve health data systems literacy

2 To propel top-down change through public pressure, we all need to become more health data systems literate.

Bottom up integration of PGHD

3 We need to find ways to collect and add/link PGHD to existing health records.

Open Dialogue

Topics for consideration

What to measure

- What's the value of measuring something if no one is using it?
- How to know what people care about?
- How have you assessed whether you're asking the right questions?

Advances in AI & Digital Health

- What is the risk/opportunity for AI when it comes to person-centred research?
- What will advances in digital health mean for RWE applications?

Broader value proposition

- What is the broader value proposition for the use of PGHD and patient-centric best practices in the evidence used for HTA and decision-making?

APPENDIX

PGHD Principles

- **Patients/caregivers as partners**

- **Purpose-driven** collection, sharing and use

- **Access** by patients should be immediate and equitable

- **Consent** by patients/caregivers to the sharing and use of data

- **Transparency** about the PGHD tool, data collectors and users

- **Harm prevention** and **Trust** from PGHD policies, safeguards, tool design and data quality

- **Utility** of PGHD data and design of tools