

Precision Psychiatry Through a Lived- Experience Research Lens

Michelle Colder Carras, PhD

Advancing User/Survivor
Involvement and Leadership in
Research

Background

- Lived experience (LE) researcher—a new profession
- Advancing User/Survivor Involvement and Leadership in Research
- Public mental health scientist and health science consultant, deep interest in Agile project management
- Mental health advocate, person with lifelong LE of mood disorder
- Paid consultant in academia, web- and XR startups, and entertainment industry

Note: I will use medical terms like illness, disorder, and patient for ease of discussion, but these don't capture the full range of identity and experiences for people living with mental health problems.

▸ Precision Psychiatry's Core Problem

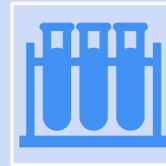
- Standard psychiatric care rarely uses **systematic longitudinal measurement**; patients' reports of experience—the main data source—is treated as **noisy**, while clinician impressions anchor diagnosis and treatment.
- Visits are often unstructured and months apart, so **learning and course correction to better personalize care is slow**
- The problem: Precision psychiatry would need rapid feedback and response to multiple new sources of information, but in psychiatry our primary signal is **infrequently captured, underweighted, or even treated with doubt.**

Because psychiatric treatment can be **involuntary**, we have a *strong ethical obligation* to get personalization right.

▶ Lived Experience Research: A View From the Trenches



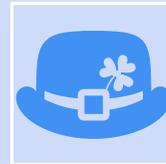
30 years ago: SSRI treatment → nausea → “push through it”



15 years ago: pharmacogenomic testing



3 weeks ago: Learned of drug interaction reducing my mood stabilizer effectiveness for the past **2 years**



1 week ago: Paid out of pocket for a med that I know works. **Depression vanished.**

As a LE researcher, I’m very privileged. What do we owe less privileged and more vulnerable patients in terms of precision and protection?

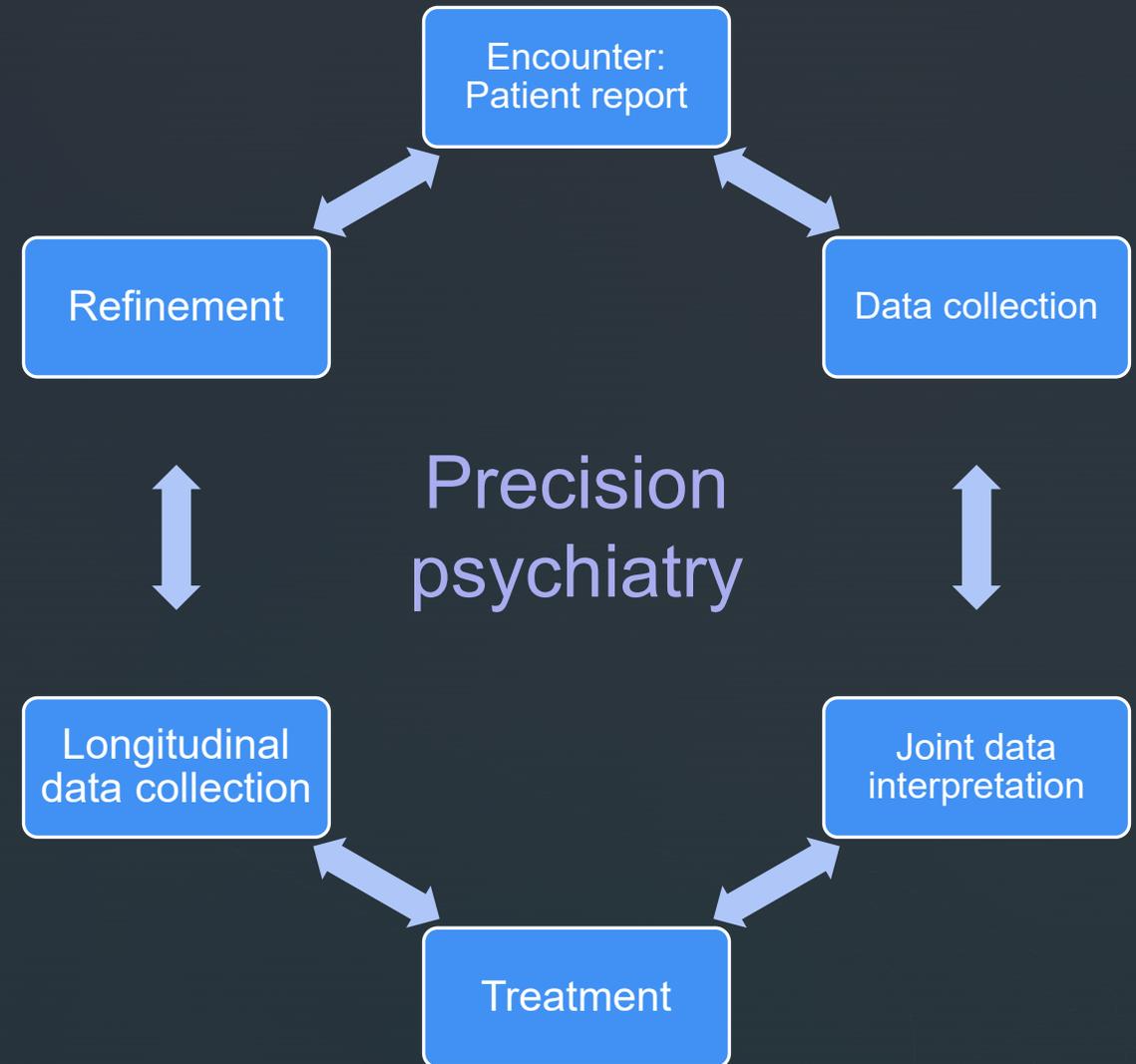
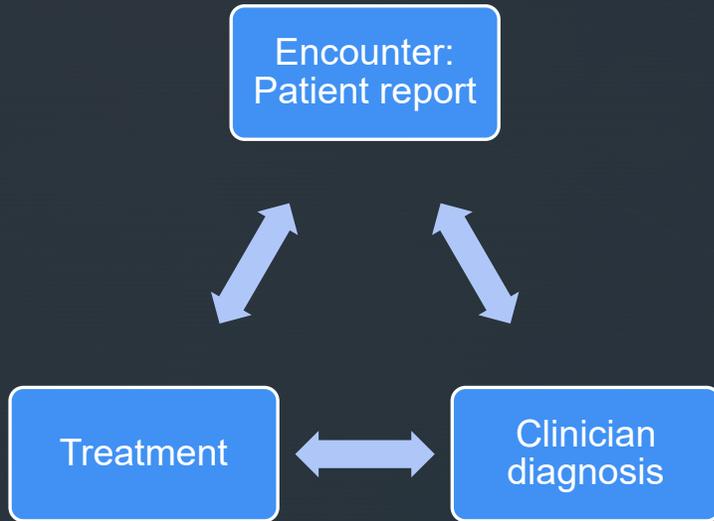
Data, Labels, and Meaning

- **Doubting** our main data source can lead to misattribution or labels.
 - “Suicidal because he has more energy”
 - “Nausea will resolve; push through it”
 - “Difficult”, “Noncompliant”,
- **Subtypes exist but aren’t identified:** genetic, immune, metabolic—in some cases cure is possible
- Few guidelines/workflows; time to “treatment that works” can take years

What do we need to transform this fuzzy process to one based on measurement, meaning-making, and learning from rapidly iterated changes?

Agile Approach for Precision

Traditional psychiatry



What Needs to Change: Clinical Practice



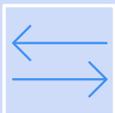
Strengthen systematic longitudinal measurement-add structure to interactions



Work with patients to interpret and act on all available; prioritize the data and insights they want



Practice epistemic humility- keep interpretations flexible, remove judgments, be curious, embrace uncertainty and change

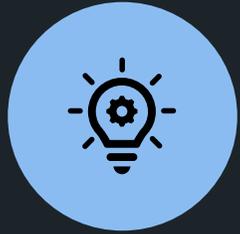


Iterate rapidly, get biomarkers if treatment isn't a "slam dunk"



Lower the bar for preventive testing and raise it for minimizing potential harm

What Needs to Change: Research & Ecosystems



ENSURE PATIENT EXPERTISE IS INCLUDED AT ALL STEPS:
LIVED-EXPERIENCE RESEARCHER LEADERSHIP CAN HELP.



USE ETHICS TO DRIVE POLICY AND ORGANIZATIONAL CHANGE.



USE MEASUREMENTS AND METHODS THAT PATIENTS PREFER



BORROW FROM AGILE: ENSURE PATIENTS AND CLINICIANS WORK TOGETHER TO ACT ON DATA AND CAN PIVOT RAPIDLY



MOVE FASTER TO BRING PRECISION PSYCHIATRY TO PRACTICE

Precision Psychiatry is About Learning

- Not perfect biomarkers
- Not cutting-edge digital tools
- Not perfection

If we can:

- Learn from patients
- measure meaningfully
- interpret together and
- embrace change

We can build systems based on **continuous learning and judgment-free pivots**



For more information

[Email: michelle@carrasandco.com](mailto:michelle@carrasandco.com)

Advancing User/Survivor
Involvement and Leadership in
Research (AU/SIR)

www.livedexperianceresearch.org

Carras Colder Carras, LLC
www.carrasandco.com

Thank you to:

Peter Zandi & Fernando Goes-Johns Hopkins
Stanley and Elizabeth Star Precision Medicine
Center of Excellence in Mood Disorders

Lilliam Rosario, TransCelerate BioPharma

Laura Bustamante, Nev Jones, Emily Turner,
Matthew Jackman and the (AU/SIR) coalition

Incredible family, friends and clinicians

