Co-creating Pain Therapeutics: Where Innovation Meets Lived Experience

Christin Veasley
Co-Founder & Director
Chronic Pain Research Alliance

No disclosures.

The Widespread Impact of Chronic Pain

Physical Impact

Emotional Toll

Financial Burden

Social Impact

Chronic Pain Treatment: Trial and Error

"Unfortunately, the field of chronic pain treatment is strikingly deficient in high-quality scientific evidence."

~ Former FDA Commissioner Dr. Robert Califf

NEJM 2016;374:1480-5.

Ending the "Trial & Error" Era
The Cost of Failed Treatments

Try Treatment

Hope and anticipation

Wait for Results

Uncertainty and patience

Experience Failure

Repeated disappointment and setback

Start Over

Emotional and physical toll

> *“I lost years of my life to ‘let's see if this works.’”*
> *"We need to move beyond 1-by-1 trial-and-error to right-treatment-for-the-right-person-at-the-right-time."*

Real-World Decisional Dilemmas: Risk-Benefit Decisions are Complex

Efficacy

Does it reduce pain?

Side Effects

What new problems arise?

Life Impact

How will it affect my life & function?

Financial Burden

Is it covered? Can I afford it?

Time & Logistics

Appointments, recovery, travel?

"We are not just choosing a treatment - we are choosing how to live.“

“A treatment that helps pain but leaves me unable to work or function isn't success—it's just a different kind of suffering.”

Multiple Conditions, Multiple Decisions

Multiple Pain Conditions

Co-occurring Disorders

Multimodal Treatment

Efficacy

Does it reduce pain?

Side Effects

What new problems arise?

Life Impact

How will it affect my life & function?

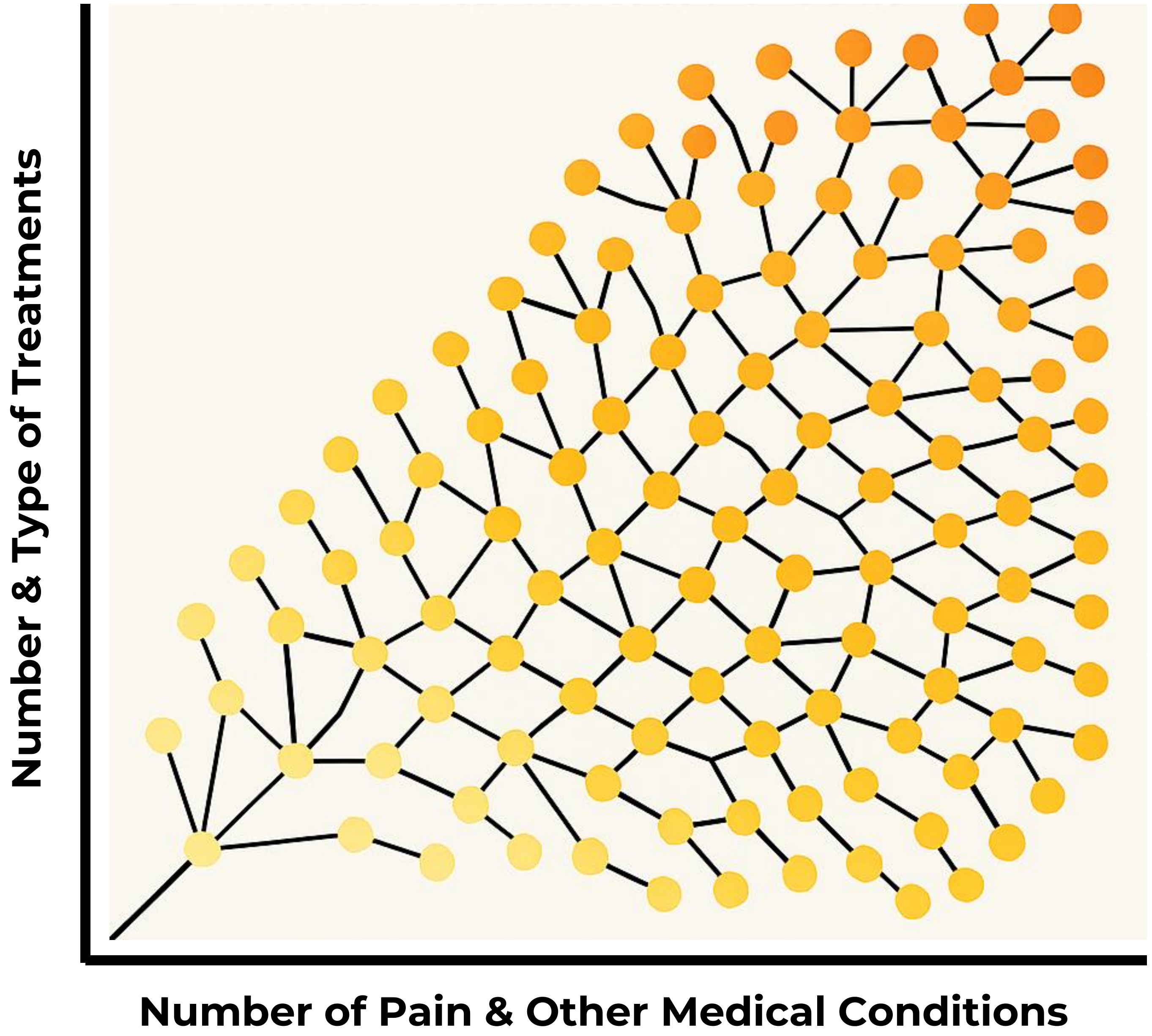
Financial Burden

Is it covered? Can I afford it?

Time & Logistics

Appointments, recovery, travel?

Increasing Complexity of Risk-Benefit Decisions Patients Have to Make



Ending the “Trial & Error” Era
The Need for Better Data & Personalization

Subtyping & Prediction

Data to identify which treatments work for whom & predictors of success.

Combination Effect

Study additive effects of treatment combinations (drug, non-drug, procedures/surgical, behavioral).

Meaningful Metrics

Prioritize outcomes that matter to patients - function, sleep, mood, etc.

Long-Term Data

Extend the length of studies to collect long-term efficacy data.

"If treatments are developed with us, they're far more likely to work for us."

How Do We Get There? Partnering with Patients

1. **Treatment & Research Design**

   Patients improve design and meaningfulness.

2. **Development**

   Patient feedback shapes usability and practical application.

3. **Testing**

   Real-world testing with diverse patient populations.

4. **Implementation**

   Patient advisors guide rollout and education.

"If treatments are developed with us, they're far more likely to work for us."

Benefits of Engagement

Better Relevance

Treatments address what matters most to patients.

Increased Uptake

Patients more likely to adopt solutions they helped create.

Enhanced Trust

Collaboration builds confidence in medical innovations.

Improved Outcomes

Treatments aligned with patient realities work better.

Vision for the Future – Co-developed with Patients

Better Treatment Data

Data on long-term efficacy, predictors & combination benefits.

Personalized Treatments

Right treatment for the right person at the right time.

Whole-Person Outcomes

Success measured by improved quality of life, not just pain reduction.

> *“The future can be better if we do it together."*

Engagement Resources

Comprehensive Review

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Patient engagement in designing, conducting, and disseminating clinical pain research: IMMPACT recommended considerations

Simon Haroutounian[a,*], Katherine J. Holzer[a], Robert D. Kerns[b], Christin Veasley[c], Robert H. Dworkin[d], Dennis C. Turk[e], Kristin L. Carman[f], Christine T. Chambers[g], Penney Cowan[h], Robert R. Edwards[i], James C. Eisenach[j], John T. Farrar[k], McKenzie Ferguson[l], Laura P. Forsythe[f], Roy Freeman[m], Jennifer S. Gewandter[d], Ian Gilron[n], Christine Goertz[o], Hanna Grol-Prokopczyk[p], Smriti Iyengar[q], Isabel Jordan[g], Cornelia Kamp[r], Bethea A. Kleykamp[s], Rachel L. Knowles[t], Dale J. Langford[u], Sean Mackey[v], Richard Malamut[w], John Markman[x], Kathryn R. Martin[y], Ewan McNicol[z], Kushang V. Patel[e], Andrew S.C. Rice[aa], Michael Rowbotham[ab], Friedhelm Sandbrink[ac], Lee S. Simon[ad], Deborah J. Steiner[ae], Jan Vollert[aa,af,ag,ah]

Abstract

In the traditional clinical research model, patients are typically involved only as participants. However, there has been a shift in recent years highlighting the value and contributions that patients bring as members of the research team, across the clinical research lifecycle. It is becoming increasingly evident that to develop research that is both meaningful to people who have the targeted condition and is feasible, there are important benefits of involving patients in the planning, conduct, and dissemination of research from its earliest stages. In fact, research funders and regulatory agencies are now explicitly encouraging, and sometimes requiring, that patients are engaged as partners in research. Although this approach has become commonplace in some fields of clinical research, it remains the exception in clinical pain research. As such, the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials convened a meeting with patient partners and international representatives from academia, patient advocacy groups, government regulatory agencies, research funding organizations, academic journals, and the biopharmaceutical industry to develop consensus recommendations for advancing patient engagement in all stages of clinical pain research in an effective and purposeful manner. This article summarizes the results of this meeting and offers considerations for meaningful and authentic engagement of patient partners in clinical pain research, including recommendations for representation, timing, continuous engagement, measurement, reporting, and research dissemination.

Keywords: Pain, Clinical trials, Patient engagement, Patient partners

How-To Guides for Patient Engagement

PATIENT FOCUSED MEDICINES DEVELOPMENT

How-to guide for patient engagement in the early discovery and preclinical phases

https://pemsuite.org/How-to-Guides/Early-Discovery.pdf

Thank you!