



# Expertise and Empowerment: Why Patient Perspectives Are Central to Care

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# Indigenous Land Acknowledgement

- We respectfully acknowledge that we live and work in territories where Indigenous nations and Tribal groups are traditional stewards of the land.
- Please join us in supporting efforts to affirm Tribal sovereignty across what is now known as California and in displaying respect, honor and gratitude for all Indigenous people.

## Whose land are you on?

Option 1: Text your zip code to 1-855-917-5263

Option 2: Enter your location at <https://native-land.ca>

Option 3: Access Native Land website via QR Code:



May is **Asian Pacific  
American Heritage Month**

**Mental Health Awareness  
Month**

**Hepatitis Awareness  
Month**

Learn more at:

- <https://fapac.org/AAPI-Resources>
- <https://www.samhsa.gov/programs/mental-health-awareness-month>
- <https://www.cdc.gov/hepatitis/awareness/HepatitisAwarenessMonth.htm>



The use of affirming language inspires hope and advances recovery.

**LANGUAGE MATTERS.**

**Words have power.**

**PEOPLE FIRST.**

The ATTC Network uses affirming language to promote the promises of recovery by advancing evidence-based and culturally informed practices.



**ATTC**

Addiction Technology Transfer Center Network  
Funded by Substance Abuse and Mental Health Services Administration

# Disclosures

There are no relevant financial relationships with ACCME-defined commercial interests for anyone who was in control of the content of this activity.



# Learning Objectives

1. Specify at least two justifications for centering patient perspectives in treatment and other health care settings
2. Identify at least two methods for engaging patients as experts
3. Formulate at least two ways to empower patients by co-producing knowledge



# Why Patient Perspectives Matter

- ▶ *“...when I did see my counselor and I wanted to change something they'd tell me that they didn't feel the same way as me, or they didn't care what I was saying or, you know- It's just almost like they didn't care at all. Like they didn't see me as being a person. They just didn't even care about helping people.”*
- ▶ *“And they do take their ability to control things a little too far... Basically, they do behavior modification. But it's really intimidating, it's scary. And I think that's a lot of times why [people who use drugs] don't seek treatment, honestly. I left. I didn't have anywhere to go. But I didn't want to be brow-beated and intimidated.”*





# Why Patient Perspectives Matter

- ▶ *“I feel like I do have a lot of say in it... And I feel like it's a safe place for me to be. It's a safe environment... I've been able to raise and or lower my dose as needed. And there has been no judgment or pressure. And there are regular treatment plans done where I get to say what aspect I want to work on.”*

# Landscapes of Care



Reference: Puig De La Bellacasa, M. (2015). Making time for soil: Technoscientific futurity and the pace of care. *Social studies of science*, 45(5), 691-716.

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# Knowledge and Expertise in Care

- ▶ “Being involved in decision-making on a superficial level was described as a source of powerlessness. For example, psychiatric patients described not feeling a sense of true freedom in decision-making because of the physician’s ability to force medication... For some patients, ‘As a result of perceived implicit coercion, real choice did not seem an option...’ Other patients, who were accustomed to the standard hierarchical relationship between medical professionals and patients, ‘had simply not considered patient choice as an option in their care’” (p. 2056).

Agner, J., & Braun, K. L. (2018). Patient empowerment: A critique of individualism and systematic review of patient perspectives. *Patient Education and Counseling*, 101(12), 2054-2064.



# Knowledge and Expertise in Care

- ▶ What knowledge/facts are contributing to how decisions are being made in the first place?
- ▶ Who creates that knowledge? Who is an expert?

# The *Your Voice, Our Community* Project



- ▶ Survey participants recruited to research team - “Steering Committee”
- ▶ Provided with compensation and scientific training
- ▶ Analyze/interpret survey results in collaboration with institutional researchers
- ▶ Determine how to disseminate findings
- ▶ Define new research questions/evaluation projects



# Other Examples

- ▶ Community Driven Research: [North Carolina Survivors Union](#)
- ▶ Drug Policy Alliance: Beyond Participatory-Based Research  
[bit.ly/BeyondCBPR4](https://bit.ly/BeyondCBPR4)  
May 23, 1:30 PT
- ▶ California Harm Reduction Initiative
- ▶ North American Syringe Exchange Network (NASEN)  
<https://www.nasen.org/map/>
- ▶ Peer Support Organizations/Peer Respite  
<https://power2u.org/directory-of-peer-respites/>



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