



## **Leveraging Qualitative Research to Highlight Social Determinants of Health:**

Introducing the Health Experiences Research Network (HERN)

# Representatives from HERN



Njeri Grevious (she/they)



Rachel Grob (she/her)



Nancy Pandhi (she/her)



Kate Smith (she/her)



# Overview

## Brief History & Context



# HERN in Context

We are also part of an international group of 14+ countries using a similar health experiences research methodology, Health Experiences International (formally DIPEX) methodology.



Health Experiences International is an internationally vetted qualitative approach to rigorously eliciting, synthesizing, and disseminating health experience narratives; it is considered the gold standard for health experience research.



# What is HERN?

Founded in 2014, **HERN** is a research consortium dedicated to elevating patient voices through Health Experiences International (formerly DIPEX) methodology.

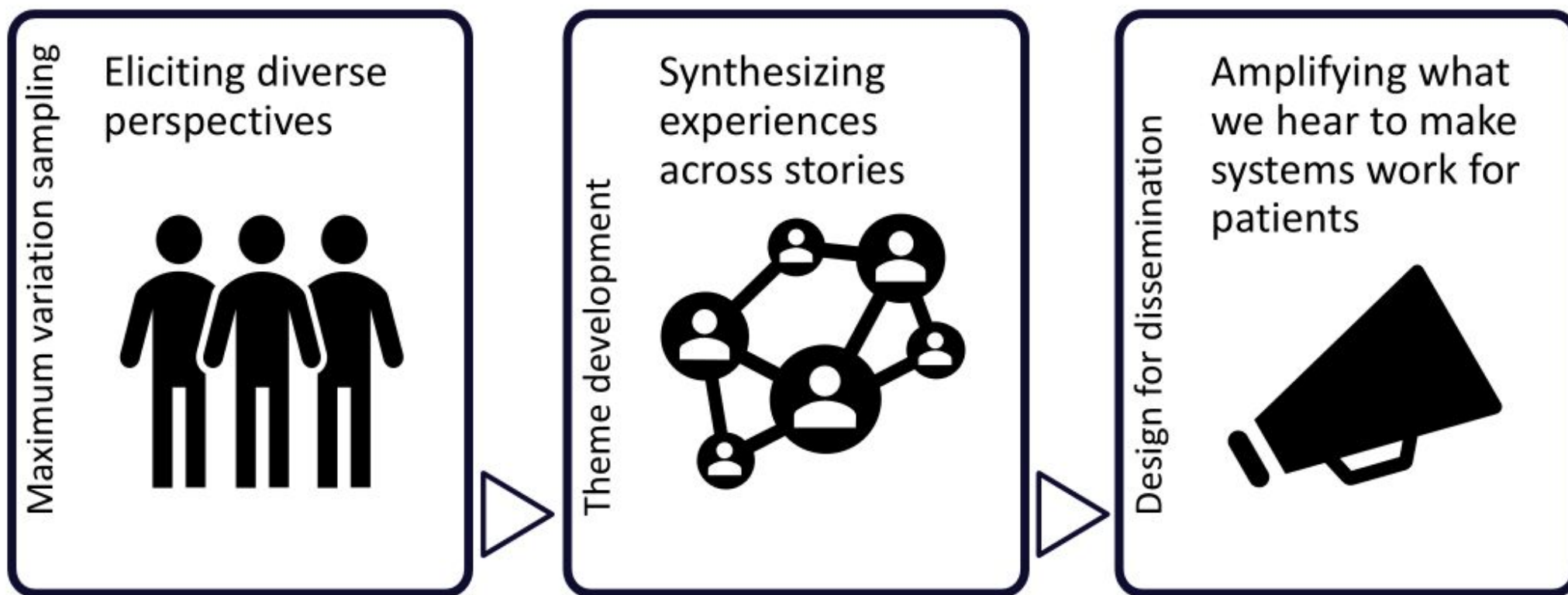
This methodology stems from UK's Oxford Health Experiences model whose approach emphasizes **deep, narrative-based qualitative interviews** (typically 30–50 per module). Our research is conducted across the U.S.

We use **maximum variation sampling** to capture a wide range of lived experiences, not just demographics, but social and structural context.



# Social Determinants of Health (SDOH) @ HERN

HERN research complements social determinants of health (SDOH) research by elevating rigorously analyzed narratives in the US to surface the lived realities behind different lived experiences of social determinants.



# Mission and Mechanisms

**Mission:** Elevate and disseminate rigorously collected patient narratives to shape clinical practice, policy, and research.

## Publicly Accessible Web Content:

- Organized thematically with transcript excerpts, audio and video clips
- **8 Modules, 6 Catalyst Films, 1 Pilot** (and counting!)

**Cumulative Impact (as of July 2025):** ~447K new users and ~504K total sessions (and counting!)



# Catalyst Films leveraging EBCD in US health context

- Catalyst films are a powerful complement to HERN's web modules and use EBCD to offer immersive, thematic storytelling that highlights the structural and social forces shaping patient experiences.

## Experience-based co-design (EBCD)



- These films allow us to spotlight particularly complex or underexplored issues within a module, often surfacing key Social Determinants of Health (SDOH) including housing, access, and stigma.

Young Adults' Experiences with Depression

  
A Catalyst Film

*The Depression Catalyst Film examines mental health through a social and structural lens, highlighting real patient stories that are often overlooked in traditional clinical settings. It challenges common assumptions and brings attention to the broader social factors that shape mental health outcomes.*

Catalyst films are an additional tool in the “patient” engagement toolbox” that provide a robust, broad representation of health experiences.

Davis S, Pandhi N, Warren B, et al. Developing catalyst films of health experiences: an analysis of a robust multi-stakeholder involvement journey. *Res Involv Engagem*. 2022;8(1):34. doi:10.1186/s40900-022-00369-3



# What sets HERN apart



HERN is not just “a person with a camcorder” interviewing patients.

It’s a rigorous, co-produced methodology

What sets HERN apart is the **intentionality** that’s not just storytelling



# Njeri's Story

## Patient Engagement Journeys: Njeri's Story

2015



Depression Module  
Participant

2016



Depression Module  
Advisory Board &  
Ambassador

2017



Steering Committee

2024



Patient/Consumer  
Advisor



I've believe in HERN work as a model of bi-directional engagement and community-building that echoes themes important to SIREN and that were highlighted at this year's NRM such as trust and accountability.



**Our motivations**

**Why we love this work**



# Modules with SDOH

Where Social Determinants of Health Appear



# Examples of SDOH Themes

## Lived Experiences

- Health, not just health care
- Context within which illness/disease occurs
- Experiences with:
  - work, education, and managing family responsibilities
  - housing and transportation
  - bias and discrimination
  - support, community, advocacy, learning
- Insurance and financial issues

HIGHLIGHTING CONTENT  
FROM OUR BREAST  
CANCER MODULE

Carrie, Kawanna, Maria, Katrina





# Lived Experiences

Even though Carrie had insurance, undergoing treatment led to bankruptcy.





## Lived Experiences

Kawanna worked throughout her illness to stay afloat financially.





## Lived Experiences

Maria de Los Angeles was turned away from a clinic because she was uninsured.

*English translation: So, I waited a few weeks for the results, and they called me and said that they wanted to speak with me in person, and then they told me that it was cancer. Yes, it was hard. I was worrying because we didn't have the means, the money. And as a Hispanic or Latino, well, one worries, right? That what if the medical insurance... We searched for information. They sent us to a clinic where, by the way, since I didn't have insurance, they rejected my first appointment.*





## Lived Experiences

Katrina worries that being on Medicaid means receiving lower quality care.



# Exploring SDOH in HERN Modules

## **Living with Gulf War Illness: Messages, Lessons, and Recommendations for other Veterans and Service Members**

<https://www.healthexperiencesusa.org/Gulf-War-Illness/Messages-Lessons-and-Recommendations-for-Other-Veterans-and-Service-Members>

“Messages and recommendations primarily fell under these categories: accessing resources, coping with life after the military...obtaining support, and education”

## **Traumatic Brain Injury in Veterans: Services & Programs for Veterans**

<https://www.healthexperiencesusa.org/Traumatic-Brain-Injury-in-Veterans/Getting-Care-at-VA>

“One Veteran talked about using services provided for rental assistance and food stamps. A Veteran from the Vietnam era we interviewed said he did not know about all of the services available to him when he was first struggling with his condition”

## **Living with MS: Work and School**

<https://www.healthexperiencesusa.org/Multiple-Sclerosis/Work-and-School>

“Grace worried about the long-term ramifications of not working on saving for retirement and Kara described being eager to return to her job after her diagnosis because she has bills to pay. Despite the impact of symptoms on their job experiences, many people discussed the need to work”.



# HERN Applications

## Education



# Broadening Medical Students' Exposure to the Range of Illness Experiences: A Pilot Curriculum Focused on Depression Education

Nancy Pandhi, MD, MPH, PhD, Martha Gaines, JD, LLM, David Deci, MD, Mark Schlesinger, PhD, Cecilia Culp, MA, Zaher Karp, MPH, Christie Legler, and Rachel Grob, PhD, MA



## Abstract

### Problem

Exposing medical students to a broad range of illness experiences is crucial for teaching them to practice patient-centered care, but students often have limited interaction with patients with diverse illness presentations.

### Approach

The authors developed, implemented, and evaluated a self-directed online curriculum followed by a small-group discussion focused on depression education. The curriculum was based on a module created using the Database of Individual Patients' Experiences methodology. Findings from 40 interviews with young adults across

the United States about their diverse experiences with depression were summarized online, and the summaries were illustrated by video, audio, and text clips. From August 2016 to April 2017, third-year students completed either this online curriculum and the usual clerkship curriculum or just the usual clerkship curriculum. These intervention and control groups completed pre- and postsurveys.

### Outcomes

Students in the intervention group reported that the online curriculum influenced their thinking about depression (51/56) nearly as often as they reported that seeing patients in

clinic did (53/56). They also reported greater decreases in personal stigmatizing attitudes toward depression than did students in the control group as measured by the Depression Stigma Scale (5.75–4.02, intervention; 6.50–5.65, control;  $P = .004$ ). In open-ended responses, students in the intervention group were 13 times more likely to describe key lessons from the curriculum that reflected patient heterogeneity.

### Next Steps

Future collaborations include implementing and evaluating this curriculum at other medical schools and developing additional versions based on other illness experiences.



# Helping all UNM Residents Think about SDOH

- Case-Based workshop offered on the first day of Graduate Medical Education orientation
- Illustrated by vignettes from the HERN website
- View cases as a large group
- Discussions facilitated by experienced Faculty

Materials developed by and displayed with permission from the current UNM GME leadership team: Drs. Miranda Aragon & Natalie M. Salas

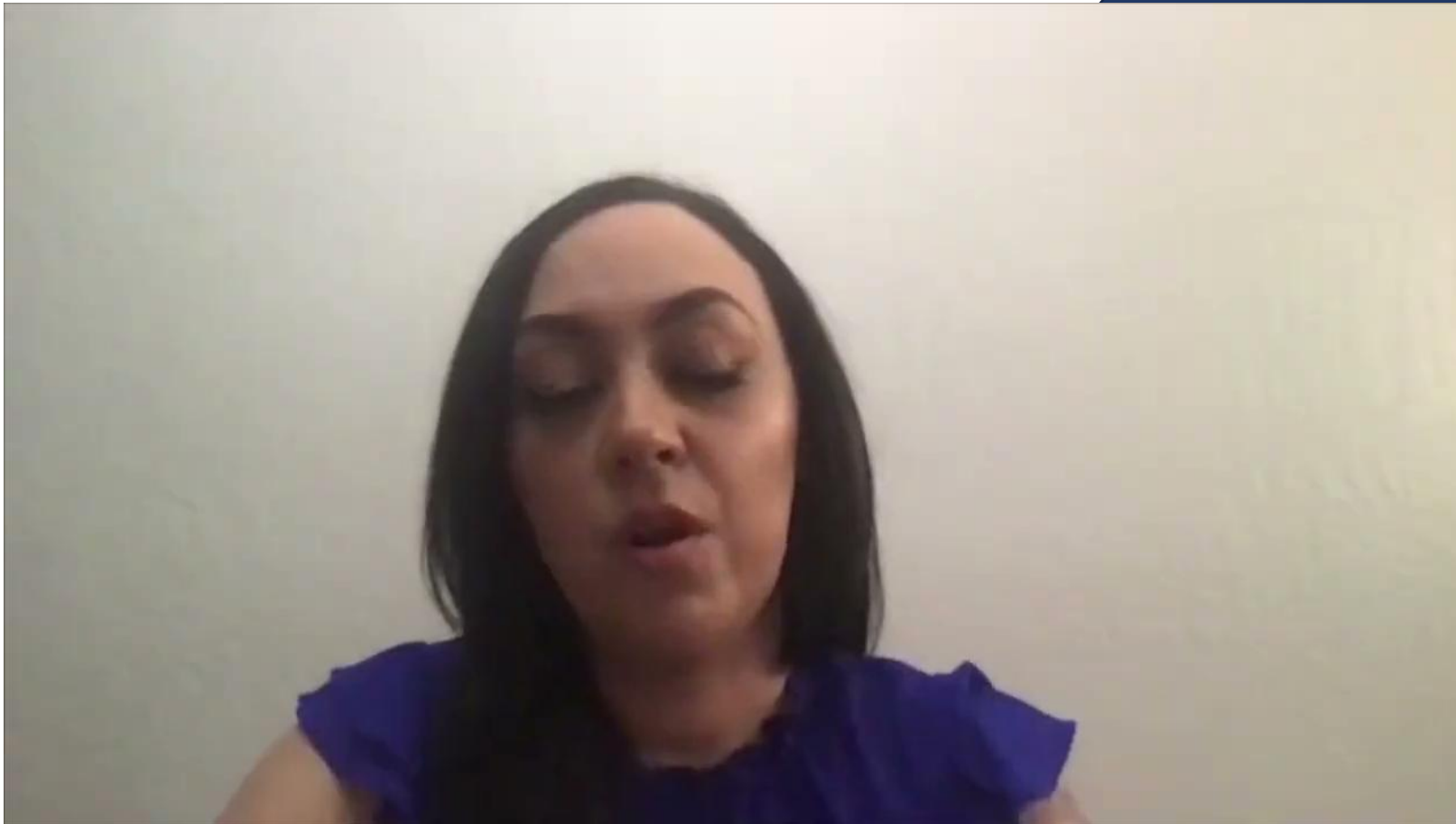
Gratitude also to Dr. Suman Pal, now at UMN, who initially fostered this collaboration and participated in curricular development



# Vignette Example

- Zoe lives in Deming, New Mexico (see map) and her daughter Sofya has kidney failure from post streptococcal glomerular nephritis.
- Sofya was approved for a kidney transplant, but few family members were available to test for donor eligibility. Sofya's biological father has had no contact with the family for several years and Zoe has no other children.
- Luckily, Zoe was found to be a donor match! She was initially elated that her ability to be a donor would spare her daughter months of dialysis.





# Lived Experiences

Travel barriers and delays in testing



# List of Zoe's appointments required prior to kidney donation

- . Primary care appointment for physical exam
- . Primary care appointment for cervical cancer screening
- . Laboratory appointment for testing
- . Mammogram appointment
- . Dental appointment for routine evaluation (able to do in Deming)
- . Dental appointment for filling for cavity found on evaluation
- . Behavioral health appointment for psychological assessment
- . Echocardiogram
- . Appointment with Nephrology
- . Kidney Ultrasound
- . Interventional radiology appointment for kidney biopsy



# Facilitated discussion questions

1. When a patient is scheduled for several appointments at a tertiary center, what assumptions are we making about the patient for them to be able to adhere to the care plan?
2. What if Zoe and Sofya were from Gallup and had Indian Health Service insurance
3. What ideas do you have about how we could redesign outpatient health care to better support New Mexico's large rural population?



# Closing

- After several months on dialysis, Sofya undergoes an uncomplicated live kidney transplant surgery with a kidney donated by Zoe. While recovering from surgery in the hospital, they share a hospital room. Zoe shared that this was hard for her because she did not want Sofya to see her in pain.
- The hospital coordinated a hotel room for them to stay in for the month after discharge, and this helped significantly with transportation and making it to their many appointments in the post-op period.
- Sofya has not required dialysis since transplant.



# Call to Action

We want to partner with you!



# How to Get Involved 🤝



## **School Curricula:**

Embedded in medical and public health training



## **Clinical Education:**

Empathy and awareness building tools for providers



## **Policy:**

Humanizing data to accompany advocacy work



## **Toolkits:**

HERN modules are cited and linked in national toolkits and research grants



## **Funding Collaboration:**

Partner to secure new grants and funding opportunities



## **Research:**

Narrative data for secondary analysis





**Save the Date!**  
**HEALTH EXPERIENCES RESEARCH**  
**2026 Training**  
**Tentative dates: May 18-21**

For updates, please contact [HERNTraining@salud.unm.edu](mailto:HERNTraining@salud.unm.edu)

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Instructors from: University of Wisconsin-Madison • Oregon Health & Sciences University • University of New Mexico •  
University of Utah School of Medicine • John Hopkins Bloomberg School of Public Health • Yale School of Public Health





# THANK YOU!

Follow us on Instagram @healthexusa

Check out our website:  
[HealthexperiencesUSA](https://HealthexperiencesUSA.com)



# Discussion

