Amplifying Patient Voices:
An Innovative Approach for Understanding and Disseminating Patient Health Experiences

Erika Cottrell, PhD, MPP

OCTRI Research Forum
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• Background and history: Origins of the Database of Individual Patient Experiences (DIPEx) and the US Health Experiences Research Network

• Examples of completed and ongoing DIPEx projects (called ‘modules’)

• How can this approach be used to amplify patient voices in clinical and translational research?
Dr. Cottrell is a founding member of the Health Experiences Research Network (HERN) Steering Committee.

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Accelerating Data Value Across a National Community Health Center (ADVANCE) Clinical Research Network, Patient-Centered Outcomes Research Institute (RN-CRN-2020-01)
Brances of the same tree

Sir Iain Chalmers

Dr. Ann McPherson (GP and writer, 1945–2011)
Dr. Andrew Herxheimer (clin pharmacologist, 1925–2016)
Sue Ziebland (sociologist and qualitative researcher)
Using qualitative research methods to capture people’s stories of health and illness

Original Aims:
✓ Support patients and their loved ones, who may feel alone or ill-prepared for challenges ahead.
✓ Support healthcare professionals in providing patient-focused care.
✓ Promote better communication between patients and health professionals.
Listening to patients to *capture a wide range of experiences*....

For each health condition (or module), researchers conduct 30-50 interviews.

People are encouraged to tell the story of their illness, emphasizing what is most important to them; interviews video and/or audio taped.

Aim to represent the broadest possible range of experiences (maximum variation).

Findings are disseminated via publicly-available websites; raw data is available for secondary use (upon request).
Commitment to broad dissemination

- 180+ modules disseminated via [www.healthtalk.org](http://www.healthtalk.org) (UK website)
- Data available for secondary analysis and use (with permission)
- 320+ peer reviewed publications
- Multiple uses beyond original aims...
HERN is committed to implementing the Database of Individual Patients' Experiences (DIPEX) methodology in the United States.

Partnership between researchers at University of Wisconsin-Madison, Johns Hopkins University, Oregon Health & Science University, University of New Mexico, University of Utah, Yale University.

www.healthexperiencesusa.org
HERN Steering Committee

- Mark Helfand, MD, MS, MPH
- Sara Knight, MA, PhD
- Erika Cottrell, MPP, PhD
- Njeri Grevious, BS
- Nancy Pandhi, MD, MPH, PhD
- Rachel Grob, MA, PhD (Chair)
- Kate Smith, MA, PhD
- Mark Schlesinger, PhD
- Barbara Warren, PsyD, CPXP
# HERN Modules & Pilot Projects

## Completed Modules
- Depression in Young Adults
- Traumatic Brain Injury in Veterans**
- Cancer Risk That Runs in Families
- Breast Cancer
- Childhood Cancer (in production)**

## Modules in Progress
- Gulf War Illness**
- Clinical Trials*
- Multiple Sclerosis
- Adolescent & Young Adult Cancer**
- Opioid Use Disorder**
- Firearm Injuries Among Veterans**
- COVID-19 (international comparison)

## Pilot Projects
- Cancer and Fatigue
- Long-term COVID-19*
- End Stage Renal Disease
- Adolescent Reproductive Health
- Autosomal Recessive Polycystic Kidney Disease (ARPKD)*
- Psychosis
- Living Kidney Donors
- Sexual and Gender Minority Experiences of Cancer
- Palliative Care for Young Adults*

**Led or co-led by researchers at OHSU or Portland VA
*Supported by researchers at OHSU or Portland VA
"I want my experiences to help other people, even if it’s just one person."

Health Experiences Participant

Read more about our work

ELEVATING PATIENT VOICES

The Health Experience Research Network (HERN) brings patients’ voices to American health care. HERN is a non-commercial, non-profit group, part of an international movement (DIPEx International) to share patient stories.
Why did you decide to share your story?

Why patients want you to hear their voices.
Research Team

Erika Cottrell, PhD, MPP
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Lauren Tarlow, MS
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Funding: This project was supported by the U.S. Department of Veterans Affairs, Health Services Research & Development (SDR 13-227 & FOP-15-001) and National Center for Advancing Translational Sciences (UL1TR002369).
CHANGING SENSE OF SELF

One of the biggest challenges people talked about is how their injury makes them feel inside and changes to their sense of self. Participants described feeling uncomfortable in their skin, frustrated, angry, and even afraid. Some said that injury led to career changes which impacted their self-esteem. Others described a disconnection to hobbies they once enjoyed, feeling less social, or changes to their mood or temperament.

Not being able to do what you once could

Many Veterans described the difficulty of not being able to do what you once could, “feeling like an idiot” when they couldn’t remember what they did 15 minutes ago, having more limitations than before their injury, or being “at a disadvantage compared to most people my age, my gender and my working class.”
MIGUEL

After falling from a balcony where he was employed from a high floor, landing on his head, Miguel reviews his brain injuries with life-improving outcomes. He continues to experience vertigo, memory problems, difficulty with sleep, and anger, after the accident. These symptoms are treated with medication and therapy. He also discloses his struggle with combat stress such as hyper vigilance, impulsivity, anxiety, and anger, which is a common experience for veterans. He visits a VA to cope with the veteran's readjustment. Miguel misses employment, friends, and女友s, and wants to return to his pre-injury life.

Hannah: Hi, Migration. How are you doing?
Miguel: Hi, Hannah. I'm doing okay. I'm still working on my memory and trying to stay positive.

Hannah: That's great to hear. What kind of support do you need right now?
Miguel: I need some help with memory exercises and therapy sessions. Also, I'm looking for ways to improve my sleep and manage my anger.

Hannah: I understand. We can work on those areas together. What do you think about trying some new exercises and activities?
Miguel: That sounds like a good idea. I'm willing to try anything to improve my quality of life.

Hannah: Okay, let's get started. We'll begin with some memory exercises and then move on to therapy sessions. Remember, we're here to help you every step of the way.

Miguel: Thank you, Hannah. I appreciate your help. I'm feeling better already.

Hannah: That's great to hear. Keep up the good work, Miguel.
William sustained a concussion and experienced vision loss after being caught in a rocket strike in Iraq.
Greg still struggles with memory issues; he recently took a $10 pay cut because he was forgetting important things at work.
Although Sam struggled in school initially, he found new ways to learn and to manage his workload.
Miguel talks about the misconceptions about Veterans, and the need to educate employers that not all Veterans are the same.
Jessica says it is a process, don’t quit, and celebrate your new person.
Multiple uses (beyond original aims)

- Balanced and unbiased source of information on health experiences for patients and caregivers
- Learning resource for students and health professionals
- Identify questions and problems that matter to patients; generate ideas and priorities for future research or quality improvement
- Enhance patient-centeredness of research questions; inform development of patient-reported outcomes
- Augment current community engagement activities by giving researchers access to the widest possible range of patient health experiences
- Increase understanding of the ways that social and structural factors, including structural racism, shape health experiences, outcomes, and disparities
Leveraging HERN to amplify patient voices in clinical and translational research?
Illness happens in the community

Engaging Patients in Research

“…engagement comes at a cost and can become tokenistic. Research dedicated to identifying the best methods to achieve engagement is lacking and clearly needed.” (Domecq JP et al. 2014)

If we want to conduct research that matters to patients, it is imperative to understand what is most important to them. Many organizations (e.g. VA, PCORI) calling for enhanced patient engagement in research. Limited evidence-base on how to do this effectively. Barriers to incorporating patient perspectives, values and preferences.
Amplify patient and caregiver voices in clinical & translational research

Database of Individual Patient Experiences (DIPEx)

Multiple routes of dissemination, multiple uses of information
Amplify patient and caregiver voices using a time-tested, research-based approach for conducting and disseminating health experiences research.

- Produce modules on childhood cancer, adolescent and young adult cancer, and opioid use disorder for www.healthexperiencesusa.org
- Create a repository of qualitative data available for secondary use
- Build infrastructure for sustaining HERN as a unique shared resource

Supported by National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UL1TR002369.
Childhood Cancer Module

40 semi-structured interviews with parents/guardians of children (0-14 when diagnosis; 1-5 years post-treatment)

Multiple recruitment strategies: Doernbecher; OCHIN community health centers; social media and community organizations
Patients’ voices need to be heard, which is why @healthexusa is committed to elevating their stories. Visit https://redcap.link/AYA to see if you’re eligible to share your experience of adolescent/young adult cancer and make your voice heard.
Opioid Use Disorder & Medication-Assisted Treatment Study – Study FAQ

**What is this study about?**

- Researchers at OCHIN, Oregon Health & Science University, and University of Wisconsin Madison want to better understand individual experiences with opioid use and medication-assisted treatment. With patient permission, study findings (in the form of video, audio and text clips from interviews) will be shared via a public-facing website: [healthexperiences.org](http://healthexperiences.org).

**Information for Health Centers**

- OCHIN will work with health centers to determine the best way to recruit patients (e.g., OCHIN to reach out to patients via a series of letters).
- We are seeking to interview up to 15 patients from each health center at any point in their MAT experience (e.g., starting, finished, or repeating in the last 5 years).
- Health centers will receive a $2,500 impact fee for their study participation.

**Information for Patients**

- Patients selected will be asked to participate in a 2-hour interview.
- Questions will focus on their experiences with opioid use, treatment, and stigma.
- Participants must be at least 18 years old and will receive a $50 gift card for their time.

**What is the Health Experiences Research Network?**

- This research study is a part of the Health Experience Research Network (HERN) whose primary goal is to improve health and health care by understanding patients’ diverse experiences.
- HERN is a non-commercial, non-profit group, and part of an international movement (HPERIInternational). They have created an online resource for patients, caregivers, healthcare professionals, and health systems, etc.

**What if I have questions?**

- If you have questions about the study, please reach out to Molly Kincarn, mkincarn@ochin.org
- You can also learn more about HERN by visiting [healthexperiences.org](http://healthexperiences.org) or following us on Facebook (Facebook.com/HealthExUS) or Instagram (@HealthExUS)
Commitment to Dissemination and Use

Patient Experiences Data Repository

- De-identified transcripts stored in data repository
- Available for secondary analysis, upon request

www.healthexperiencesusa.org

- Relevant, accessible information on health experiences
- Presented in lay language; illustrated with interview clips
Multiple uses (beyond original aims)

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Qualitative Data Repository

HHS Public Access
Author manuscript
Published in final edited form as:

Patient Narratives Representing Patient Voices to Inform Research: A Pilot Qualitative Study

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Portland VA Medical Center, Portland, OR, USA

Abstract

We are investigating the feasibility and effectiveness of establishing a library of patient narratives to inform patient-centered research in the U.S. Veteran Affairs organization. Using qualitative methods, we conducted a needs assessment of 15 researchers and then interviewed and videotaped 11 veterans with traumatic brain injury or diabetes. We developed a method for displaying the narratives to researchers modeled after a UK initiative called DIFEx and then performed preliminary usability testing. We found that it is not only feasible to provide researchers with patient narratives that could help guide their research, but that similar narratives might be useful to practitioners, health system decision makers, and other patients as well.

Clinical and Translational Science
dge.org/cts

Leveraging a qualitative data repository to integrate patient and caregiver perspectives into clinical research

Vivian Christensen, Kellee Parker, and Erika Cottrell

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Abstract

Understanding patient and caregiver experiences is a critical component of the conception, design, and implementation of clinical research studies. The “Database of Individual Patient Experiences” (DIFEx) is an innovative, evidence-based approach for eliciting rich information about health experiences. We conducted a formative evaluation with 14 pediatric oncology researchers to assess the value of using data from a DIFEx study on patient and caregiver experiences with childhood cancer to inform patient-centered research in pediatric oncology. Participants identified barriers to incorporating patient perspectives and experiences into their research and how the DIFEx approach could be leveraged to facilitate this practice.
“They wanted her to take less medicine... And we were like, We don’t want anymore of that study. **We’re going to stick with the 90 percent.**”

“They wanted her to take less medicine... And we were like, We don’t want anymore of that study. **We’re going to stick with the 90 percent.**”

“AALL0932-Most recent Children’s Oncology Group clinical trial for standard risk B-lymphoblastic leukemia

“I don’t know if I can deal with giving her **less medicine** and then something happens. I don’t know what I would do”

“I don’t know if I can deal with giving her **less medicine** and then something happens. I don’t know what I would do”

“Yeah. I mean, I think **that’s my biggest thing I ponder still is like had we to do it over again, would we have stayed on it once we got that diagnosis—or that trajectory of the most chemo, the most spinal taps and the most most most.”

“Yeah. I mean, I think **that’s my biggest thing I ponder still is like had we to do it over again, would we have stayed on it once we got that diagnosis—or that trajectory of the most chemo, the most spinal taps and the most most most.”
Parents reflect on their decision to continue their daughter on a clinical trial after randomization
Project Spotlight: Childhood cancer module

Dr. Kellee Parker, OCTRI TL1 Scholar and OHSU Pediatric Oncology Fellow, chose to complete her research fellowship with the OCTRI HERN team. Dr. Parker used findings from the OCTRI HERN childhood cancer interviews to develop a TL1 study to explore the factors that shape parental decision making about clinical trial participation. Findings will inform recruitment strategies, the way patients and families are educated about clinical trials, and provide insight into how parents make decisions on novel treatment.

Abstract

Background

Within pediatric oncology, parental decision making regarding participation in clinical trials that aim to reduce therapy to mitigate side effects is not well studied. The recently completed Children’s Oncology Group trial for standard-risk acute lymphoblastic leukemia (AALL0932) included a reduction in maintenance therapy, and required consent for randomization immediately prior to starting maintenance. At our institution, 40% of children enrolled on AALL0932 were withdrawn from protocol therapy prior to randomization due to parental choice. This study sought to identify factors that impacted parental decision making regarding randomization on AALL0932.
What’s next for HERN at OHSU?

- Continue to expand the network and train new investigators
- Establish governance and infrastructure for a national HERN data repository
- Enhance collaboration with researchers and communities (integrate HERN into OCTRI Community Core)
- Evaluate impact and use of modules
- Develop innovative mechanisms for dissemination (including improvements to website!)
HERN Investigators and KL2 Scholars at OHSU

Vivian Christensen, PhD
Modules: Childhood Cancer, AYA Cancer, Firearm Injuries

Shannon Nugent, PhD
Modules: Gulf War Illness, Long-COVID (pilot)

De’Sha Wolf, PhD
KL2 Pilot Study: Chronic pain among African American women

Cirila Estela Vasquez Guzman, PhD
KL2 Pilot study: Cervical cancer among Latina women
Patient experiences shared via social media, forums, blogs, YouTube etc.

Many health information sites have a few patient videos or written stories.

But.....DIPEx sites remain the only resources based on rigorous qualitative research.

Multiple uses beyond original ideas....

From 2001—2021: Is this approach still relevant today?
What makes HERN unique? Multiple uses

- Balanced and unbiased source of information on health experiences for patients and caregivers
- Learning resource for students and health professionals
- Generate ideas and priorities for future research or quality improvement initiatives
- Illuminate the health experiences of patients and caregivers from diverse and harder to reach populations
- Increase understanding of the ways that social and structural factors, including structural racism, shape health experiences, outcomes, and disparities
Web modules include a synthesis of both theme and variation across interviews, written in lay language and illustrated with clips from interviews.

Aim is to portray range of experiences, not just the most common, or those of people with the loudest voices.

Helps to avoid falling prey to “danger of a single story…”

Could hearing stories from people who are different from us help increase empathy and build bridges (as an antidote to the echo chambers of social media)?
Thank you!

Questions? Comments?

Contact:
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Visit our [website](http://www.healthexperiencesusa.org)!