

# Amplifying Patient Voices:

An Innovative Approach for Understanding and  
Disseminating Patient Health Experiences

Erika Cottrell, PhD, MPP

OCTRI Research Forum  
January 27, 2022



# Outline

- 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?

# Conflict of Interest

Dr. Cottrell is a founding member of the Health Experiences Research Network (HERN) Steering Committee.

No financial conflicts of interest to disclose.

# Acknowledgements

## Team Members:

Erika Cottrell, PhD, MPP, Principal Investigator, OHSU

Vivian Christensen, PhD, Co-Investigator, OHSU

Lauren Tarlow, MA, Research Associate, OHSU

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Tiffany Prescott, MA, Research Associate, OCHIN

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OCTRI, National Center for Advancing Translational Sciences (UL1TR002369)

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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)

# Branches 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)

# Database of Individual Patient Experiences (DIPEx)

*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)

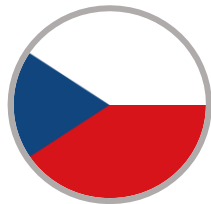
# Commitment to broad dissemination

- 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...

The screenshot displays the healthtalk.org website interface. At the top, there is a navigation bar with tabs for Home, People's Experiences, Young People's Experiences, Health Professionals, and Learning & Teaching. Below this is a secondary navigation bar with links for About, The research, News & Blog, Get involved, Scrapbooks, Register, and Login. The main header area features the healthtalk.org logo, a 'FUNDING CRISIS APPEAL' banner with a 'DONATE NOW' button, and logos for 'Health & care information you can trust' and the 'UNIVERSITY OF OXFORD'. A central menu titled 'Categories' lists various health conditions and topics, including Autism, Bones & Joints, Cancer, Carers, Chronic Health Issues, Disability & Impairment, Dying & Bereavement, Heart Disease, Improving Health Care, Intensive Care, Later Life, Medical Research, Men's Health, Mental Health, Nerves & Brain, Pregnancy & Children, Organ Donation & Transplant, and Women's Health. Below the categories is a banner with the text 'It gives us a unique look at what it's like to be on the receiving end.' and a navigation bar with links for Funding Crisis Appeal, Young People's Experiences, Health Professionals, and Learning & Teaching. The footer section includes a 'Welcome to healthtalk.org' message with a video thumbnail and a Twitter feed showing a tweet from @healthtalkorg.

# DIPEX International

[www.dipexinternational.com](http://www.dipexinternational.com)



# Health Experiences Research Network (HERN)

*HERN is committed to implementing the Database of Individual Patients' Experiences (DIPEx) methodology in the United States.*



[www.healthexperiencesusa.org](http://www.healthexperiencesusa.org)

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

# 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  
Mark Helfand, MD, MPH  
Lauren Tarlow, MS  
Sara Dolen, MS

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).

### TRAUMATIC BRAIN INJURY IN VETERANS

#### Overview

- [Nature of Injury and Diagnosis](#) ▾
- [Living with TBI](#) ▾
- [Coping and Support](#) ▾
- [Looking Forward](#) ▾
- [!\[\]\(76ef12e3b1058d749e4275db943f677e\_img.jpg\) People's Profiles](#)
- [!\[\]\(22f0b784622871c3a9489d50507338c4\_img.jpg\) Resources and Information](#)
- [!\[\]\(88dab851bd6b4c316099aae969e17f81\_img.jpg\) Credits](#)

## OVERVIEW

In this module you can learn about the experiences of Veterans who have sustained a traumatic brain injury (TBI) by seeing, hearing and reading personal stories they shared with us. Our research team interviewed 38 Veterans from across the United States. The Veterans we talked to were all asked to share the story of their injury, including when/how they first noticed something was wrong, the type of treatment or medical care they received, whether they experience ongoing symptoms, whether/how their injury has impacted different aspects of their life, how they have coped with challenges arising from their injury, and lessons they have for other Veterans who have experienced TBI.

We spoke to Veterans from a wide range of ages and eras of service. They had different experiences in the military and after their return to civilian life. Some were deployed and some were not. Some sustained their injury during their military service and others were injured after discharge. But all were united in the hope that by sharing their story, they may be able to help other Veterans struggling with similar issues.

Hear what some of the people we talked to said they would like to share with other Veterans who have experienced TBI.



[www.healthexperiencesusa.org](http://www.healthexperiencesusa.org)

## TRAUMATIC BRAIN INJURY IN VETERANS

### Overview

### Nature of Injury and Diagnosis

### Living with TBI

Living with an Invisible Disability

### Changing Sense of Self

Impact on Cognitive Function

Ongoing Physical Symptoms

Impact on Work

Impact on Family

Navigating Social Relationships

Living with TBI & PTSD

What is the Hardest Part?

### Coping and Support

### Looking Forward

### People's Profiles

### Resources and Information

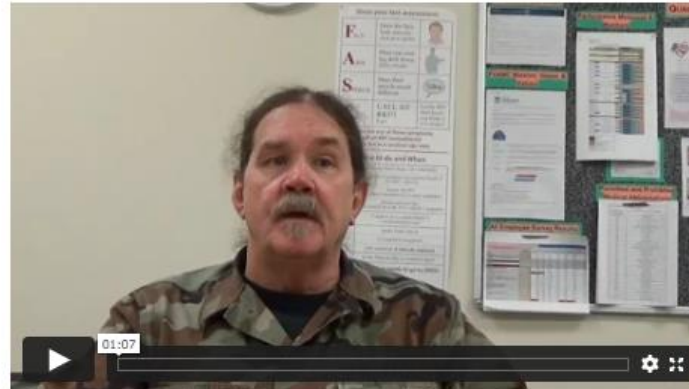
### Credits

## 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 their 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 deficiency compared to most people my age, my gender and my working class."



[SHOW TEXT VERSION](#)

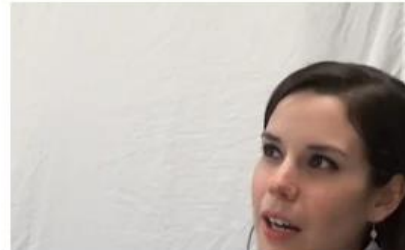
John says that for many of the younger guys, it is like going from Superman to half man.



Age at interview: 62

[View full profile](#)

[PRINT TRANSCRIPT](#)



Before her injury, Jessica says she felt like a superhero who could do all and see all, but now she has a lot more limitations.



## TRAUMATIC BRAIN INJURY IN VETERANS

### Overview

[Nature of Injury and Diagnosis](#)

[Living with TBI](#)

[Coping and Support](#)

[Looking Forward](#)

[People's Profiles](#)

[Resources and Information](#)

[Credits](#)

## MIGUEL

Age at interview: 32

### Outline:

After suffering a concussion when he was exposed to a car bomb blast during his tour in Iraq, Miguel started having problems with his vision and memory. He continues to experience vertigo, ear ringing and pain, memory problems, sensitivity to light, headaches, and also struggles with symptoms of combat stress such as hyper vigilance, depression, anxiety, and anger. With the help of family and friends Miguel sought help through the VA, to cope with the symptoms of his condition. Miguel wears sunglasses, keeps active working out, and reads and does Sudoku puzzles to exercise his brain.

### Background:

Military branch: Marine Corps

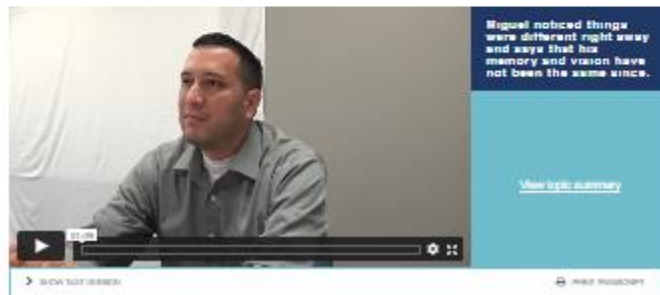
### > See full story

During a deployment to Iraq while serving in the Marine Corps, Miguel was "conducting mount and dismount of patrols" when a car bomb exploded. "I just remember looking up, hearing the sound, looking up, it happened very instantaneously, seeing a bunch of fire and then I just remember I kind of went to sleep I guess, for maybe a few seconds. I woke up and just awoke everywhere." Upon return to the battlefield and station, Miguel was told he had a concussion, among other injuries. "I think I was on bed rest four days, and then we did a quick redeployment after those four days and then we ended up going back out on patrol. So, a little eventful week, that week."

Miguel said, "I feel like my memory, my vision, my attitude, has not been the same since." He continues to experience vertigo, ear ringing and pain, memory problems, sensitivity to light, headaches, and symptoms of combat stress such as avoiding crowds, hyper vigilance, depression, anxiety, and anger. He notes that one symptom triggers others, like a "domino effect in regards to kind of going down a slippery slope." For example, he said "When I receive some bad news, it causes depression. Depression causes anxiety I feel the physiological symptoms of getting hot, and then get dizzy, and then it just goes all downhill from there... It's really the dominoes that pile to me, because it really impacts my quality of life. And unfortunately, it's an everyday occurrence. I mean, sometimes multiple times." In fact, due to the vertigo he was "denied employment for something I really wanted to do."

Soon after discharge he started "drinking a lot, as a coping mechanism to fight off the anger and the agitation." It was the support of his father, girlfriend, coworkers and friends that literally saved his life. "They saw I was going down a bad path and it was one of those where they stepped up and were very firm with me and like, "You need to go get help or you probably might not live to see your children get older." And that's kind of what scared me." With their urging, he sought help from the VA and started on medication, and effective medication through the VA. He copes with his symptoms by using sunglasses to help with light sensitivity, reading, working out, doing Sudoku puzzles, trying to learn something new every day, and "when I have them, my kids, you know, they tend to make me feel a lot better."

He urges other Veterans not to be scared to seek for help, especially for mental health. "There's a stigma surrounding mental health and Veterans feel that they're going to be looked at as psychotic if they receive mental health or that they're not going to be able to get this type of job if they get screened for TBI." He advises, "sometimes you're, you're going to have your down days. It's just how you pick yourself back up that's going to make the difference."



[Next Page](#)

William sustained a concussion and experienced vision loss after being caught in a rocket strike in Iraq.

TRAUMATIC BRAIN INJURY IN VETERANS	
Overview	
Nature of Injury and Diagnosis	▼
How Injury Occurred	
First Signs Something Was Wrong	
Evolution of TBI Awareness	
TBI Screening & Diagnosis	
Living with TBI	▼
Coping and Support	▼
Looking Forward	▼
People's Profiles	
Resources and Information	
Credits	



Greg still struggles with memory issues; he recently took a \$10 pay cut because he was forgetting important things at work.

## TRAUMATIC BRAIN INJURY IN VETERANS

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Nature of Injury and Diagnosis

Living with TBI

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Changing Sense of Self

Impact on Cognitive Function

Ongoing Physical Symptoms

Impact on Work

Impact on Family

Navigating Social Relationships

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What is the Hardest Part?

Coping and Support

Looking Forward

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Credits



Although Sam struggled in school initially, he found new ways to learn and to manage his workload.

## TRAUMATIC BRAIN INJURY IN VETERANS

### Overview

Nature of Injury and Diagnosis ▾

Living with TBI ▾

Coping and Support ▾

Coping with Impacts on Memory & Cognitive function

Coping Strategies for Day-to-Day Life

Seeking Professional Help for Emotional & Mental Health

Strategies for Managing Pain & Vertigo


Medications for Mood, Concentration & Thinking


Services & Programs for Veterans

People Who Provided Support

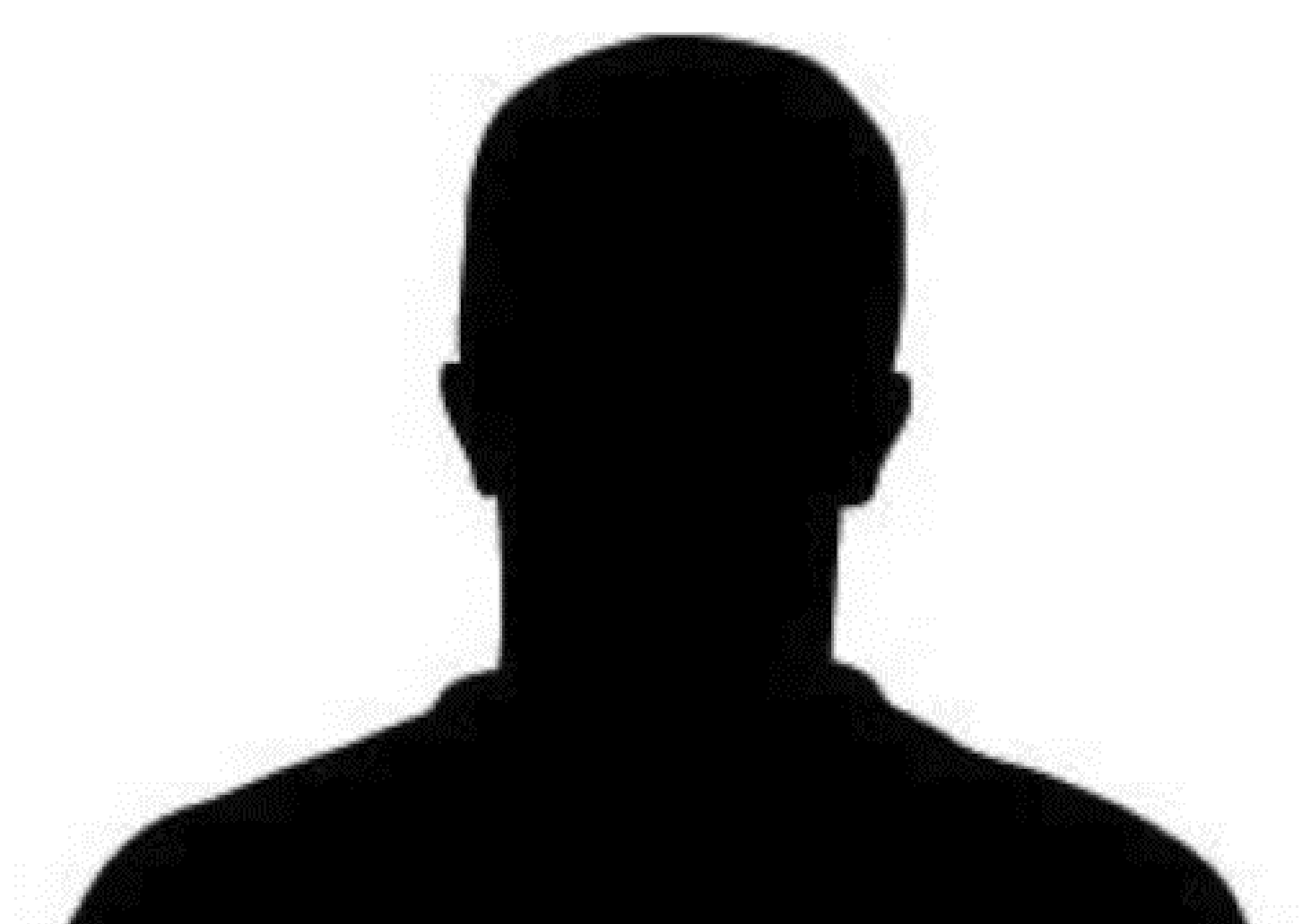
Positive Changes, Moving Forward, & Finding New Meaning

Looking Forward ▾

 People's Profiles

 Resources and Information

 Credits



Miguel talks about the misconceptions about Veterans, and the need to educate employers that not all Veterans are the same.

## TRAUMATIC BRAIN INJURY IN VETERANS

🏠 Overview

Nature of Injury and Diagnosis ▾

Living with TBI ▾

Coping and Support ▾

Looking Forward ▾

Reintegrating Into Society

Public Perceptions – & Misperceptions - of  
Veterans

Advice for Other Veterans

Unanswered Questions & Areas For Future  
Research

👤 People's Profiles

📄 Resources and Information

✍ Credits



Jessica says it is a process, don't quit, and celebrate your new person.

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Coping and Support ▾


Looking Forward ▾


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### Advice for Other Veterans

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Research

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# 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

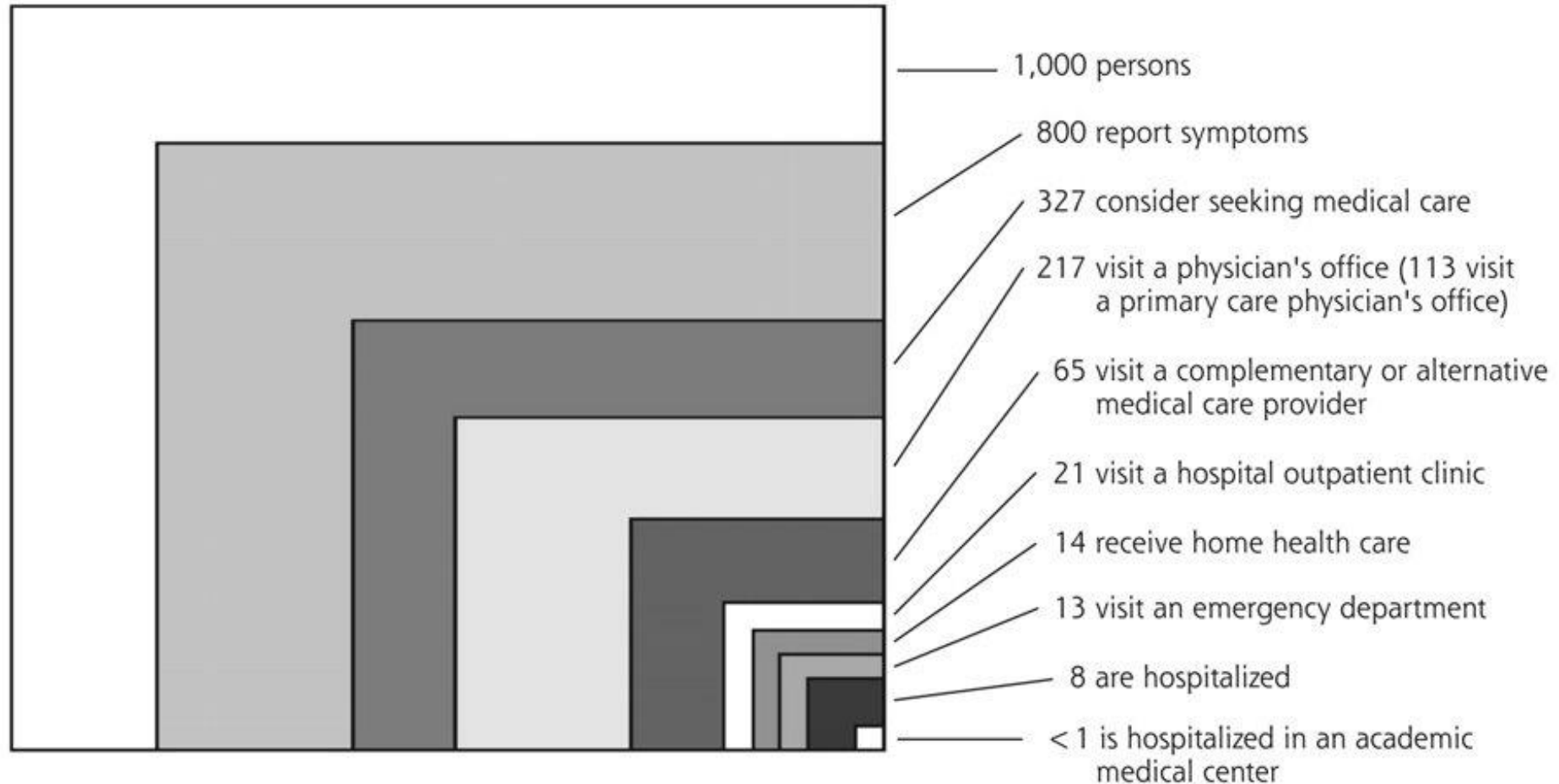
Augment current community engagement activities by giving researchers access to the widest possible range of patient health experiences

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



Green, L. A., et al. "Ecology of medical care." *N Engl J Med* 344.aa2021 (2001): 5.

# 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)*

# Amplifying Patient Voices in Research



Amplify patient and  
caregiver voices in  
clinical &  
translational  
research



Database of  
Individual Patient  
Experiences (DIPEX)



Multiple routes of  
dissemination,  
multiple uses of  
information

# OCTRI Optional Function (2017-2022)

*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](http://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

**WE WANT TO HEAR YOUR STORY**



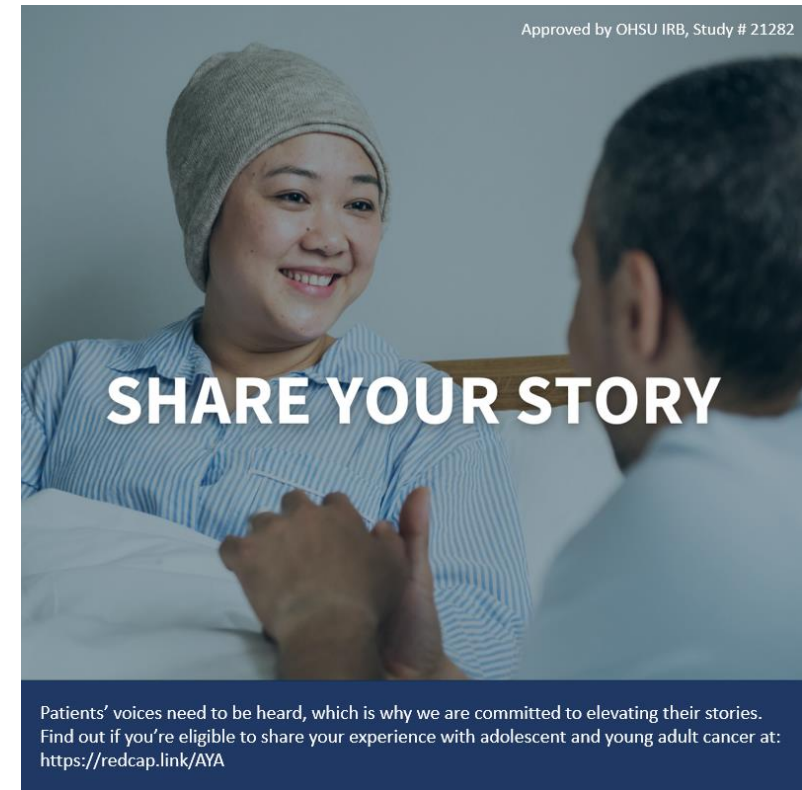
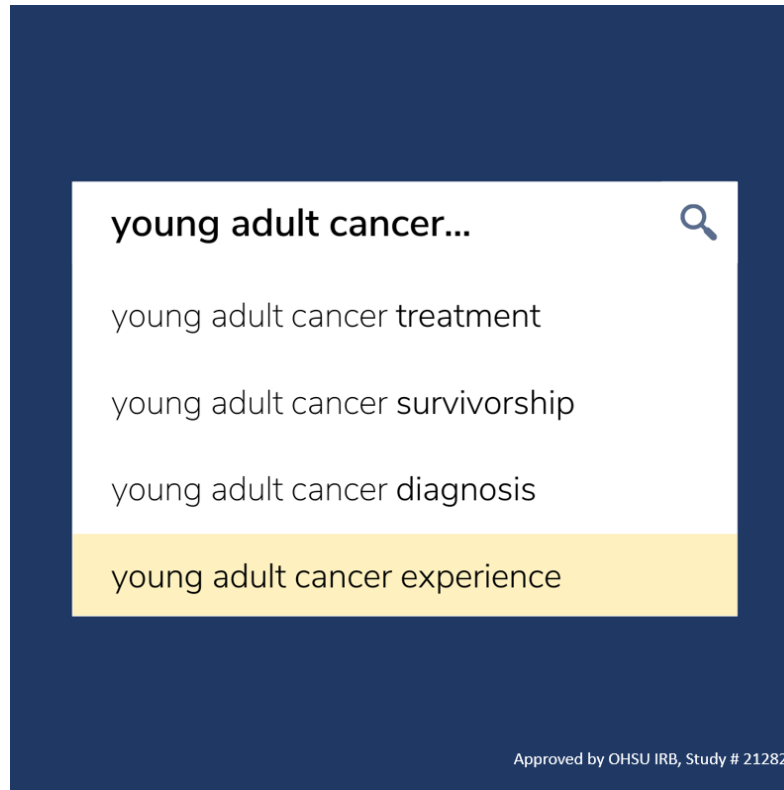
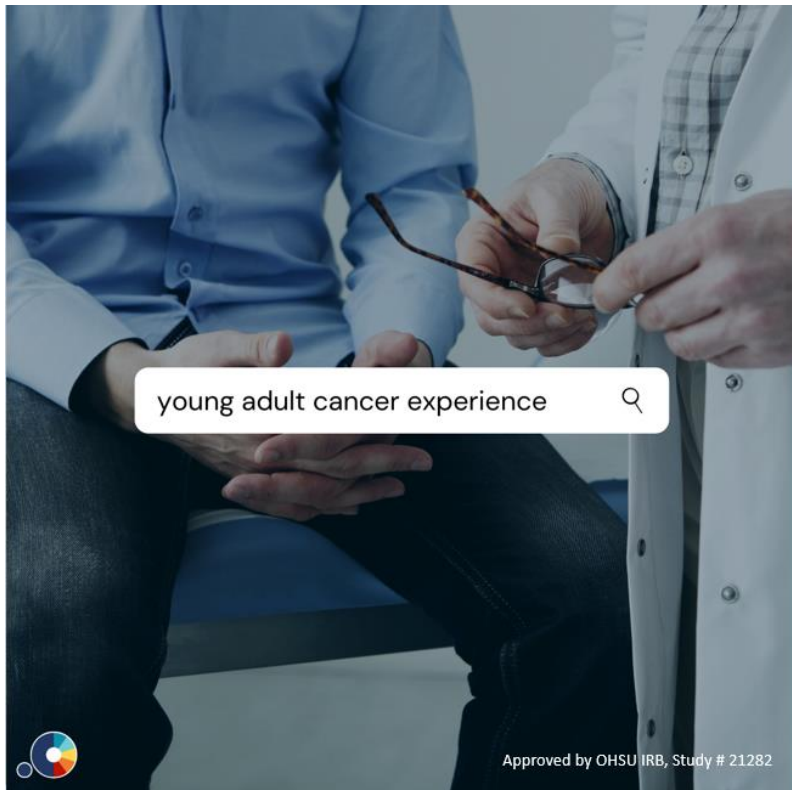
Researchers at OCHIN and Oregon Health & Science University are wanting to learn more about the experience of childhood cancer and give voice to patients and families whose stories may not otherwise be heard.

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

# AYA Cancer Study – Social Media Campaign

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

## Opioid Use Disorder & Medication-Assisted Treatment Study Information Sheet

### 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: [healthexperiencesusa.org](http://healthexperiencesusa.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?

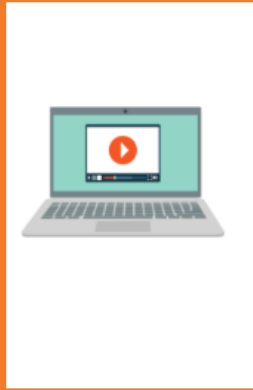
- This research study is a part of the Health Experience Research Network (HERN) whose primary goal is to improve health and health care by understanding patients' diverse experiences.
- HERN is a non-commercial, non-profit group, and part of an international movement ([DIPEx International](http://DIPExInternational.org)). 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 Krancari, [krancarim@ochin.org](mailto:krancarim@ochin.org)
- You can also learn more about HERN by visiting [healthexperiencesusa.org](http://healthexperiencesusa.org) or following us on Facebook ([Facebook.com/HealthExUSA](https://Facebook.com/HealthExUSA)) or Instagram ([@HealthExUSA](https://Instagram.com/HealthExUSA))



# Commitment to Dissemination and Use



[www.healthexperiencesusa.org](http://www.healthexperiencesusa.org)

- Relevant, accessible information on health experiences
- Presented in lay language; illustrated with interview clips



Patient Experiences Data Repository

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

# 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

# Qualitative Data Repository

Author Manuscript

Author Manuscript



## HHS Public Access

Author manuscript

Stud Health Technol Inform. Author manuscript; available in PMC 2015 April 08.

Published in final edited form as:

Stud Health Technol Inform. 2015 ; 208: 55–60.

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

Joan S ASH<sup>a,1</sup>, Erika COTTRELL<sup>a</sup>, Lauren SAXTON<sup>a</sup>, Lucas NEWMAN<sup>a</sup>, Eric GEBHARDT<sup>a</sup>, and Mark HELFAND<sup>a,b</sup>

<sup>a</sup>Oregon Health & Science University, Portland, OR, USA

<sup>b</sup>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. Veterans 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 DIPEX 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  
Qualitative Science

dge.org/cts


Qualitative Research,  
Data Analysis  
Methods

Christensen V, Parker K, and Helfand M. Integrating a qualitative data repository into clinical research. *Journal of Clinical Research*. *Journal of Clinical Research* 5: e155, 1–6. [DOI:10.1002/1.822](#)

2021  
021  
/ 2021

Keywords: patient narratives; pediatric research; translational experiences

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

Vivian Christensen<sup>1</sup> , Kellee Parker<sup>2,3</sup> and Erika Cottrell<sup>1,4</sup>

<sup>1</sup>Oregon Clinical and Translational Research Institute (OCTRI), Oregon Health and Science University, Portland, OR, USA; <sup>2</sup>Department of Pediatrics, Division of Pediatric Hematology and Oncology, University of Utah, Salt Lake City, UT, USA; <sup>3</sup>Department of Pediatrics, Division of Pediatric Hematology and Oncology, Oregon Health and Science University and <sup>4</sup>OCHIN, Inc., Portland, OR, USA

#### 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” (DIPEX) 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 DIPEX 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 DIPEX approach could be leveraged to facilitate this practice.

# Childhood Cancer Module: Clinical Trial Participation

“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.** “

“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.”

“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”

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

# Parents reflect on their decision to continue their daughter on a clinical trial after randomization



# Childhood Cancer Module: Research Generation

## 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.



## Pediatric Blood & Cancer




PSYCHOSOCIAL AND SUPPORTIVE CARE: RESEARCH ARTICLE

### Parental decision making regarding consent to randomization on Children's Oncology Group AALL0932

Kellee Parker ✉, Erika Cottrell, Linda Stork, Susan Lindemulder,

First published: 26 January 2021 | <https://doi.org/10.1002/pbc.28907>

[Read the full text >](#)

 PDF  TOOLS  SHARE

## 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

# From 2001–2021: Is this approach still relevant today?

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....

# 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

# What makes HERN unique? From voice to voices....



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)?



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

# Thank you!

## Questions? Comments?

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