

Bringing Patients' Voices to American Healthcare



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Overview

To improve depression diagnosis and treatment, researchers at UW-Madison, Johns Hopkins University, Oregon Health & Science University, Yale University, and the Veterans Administration have brought diverse patients' voices to the challenge of depression among young adults through the launch of HealthExperiencesUSA website, which has had over 50,000 annual visitors. A curriculum based on our web site is educating 760 University of Wisconsin medical students every four years and we are discussing the national expansion of the curriculum with the potential to impact over 85,000 medical students.

The Clinical Problem

Patient experience is an aspect of health and health care that has received increasing attention in the U.S. For patients and caregivers facing a new diagnosis, or needing to make a health-related decision, other people's experiences of the same diagnosis, treatments, and impact on the life course have always been valued. With the advent of web-based health information, the influence of patient experience has grown even more rapidly.

In the U.S., patient experience to date has been measured largely via quantitative national patient experience surveys. These assessments, though representative and reliable, have never been very engaging for patients, who often do not find them meaningful. Alternatively, online health information sites that do present patient experiences, often provide a few anecdotal accounts that focus on extraordinary or inspiring cases.

Our Response

The launch of HealthExperiencesUSA.org

Recognizing this gap, researchers at four universities—including UW-Madison—and the Veterans Administration formed a collaboration called the Health Experiences Research Network (HERN) in order to bring an internationally-vetted method of rigorously collecting diverse health experiences to the U.S.

"It's a move from anecdote to science. We need to do it with the assurance that we're not just collecting the outlier story, but rigorously collecting the full diversity of patients' experiences and representing them responsibly."

- Rachel Grob, PhD
UW-Madison, Department of Family Medicine & Community Health



In 2016, they launched www.HealthExperiencesUSA.org with an inaugural module on diverse young adults' experiences with depression, a disease that can have significant consequences for future social, occupational, and health outcomes.

HealthExperiencesUSA.org is the United States' version of the United Kingdom's Healthtalk.org — an online resource featuring patients' narratives that present a wide range of patient experiences organized into modules, each based on a particular illness or health condition.

The patient narratives utilize the Database of Individual Patient Experiences (DIPEx) methodology, which was developed in 2001 at Oxford University and has been adopted by researchers in 12 countries to date.

At the heart of HealthExperiencesUSA.org and Healthtalk.org is a commitment to marrying systematic qualitative research studies about patients' experiences with health and health care with development of a public-facing web-based resource (or "module"), which features video and audio clips from the studies, and can be used by multiple audiences, such as other patients, researchers, clinicians, and medical students.

"I have battled with depression for most of my life, and like the idea of being able to help others who have suffered this illness with my own story."

- HealthExperiencesUSA Participant

Who uses this type of information?

- **Patients and families** wanting to learn from the experiences of others
- **Clinicians** seeking to understand aggregate patient expectations and experience
- **Educators** wanting to include the patient perspective in teaching
- **Researchers** who want to improve health care by taking patients' perspectives into account
- **Policy Makers** eager to highlight patient experience while avoiding anecdotal accounts

Development of a medical school curriculum

The high costs and complex logistics associated with bringing patients into the medical school classroom and the variable nature of patients seen at different preceptor offices means that medical students are only exposed to a limited selection of patients' experiences in their clinical training. However, their future practice will include a broad range of patients.

With support from the Macy Foundation, faculty from UW – Madison used the module examining young adults' experiences of depression to develop and pilot test a 3-hour, online course for 3rd-year medical students in their primary care clinical rotation. The curriculum provides learners with self-directed instruction to guide their 2-3-hour exploration of website topics, and they complete brief written reflections throughout.

Lasting Impact

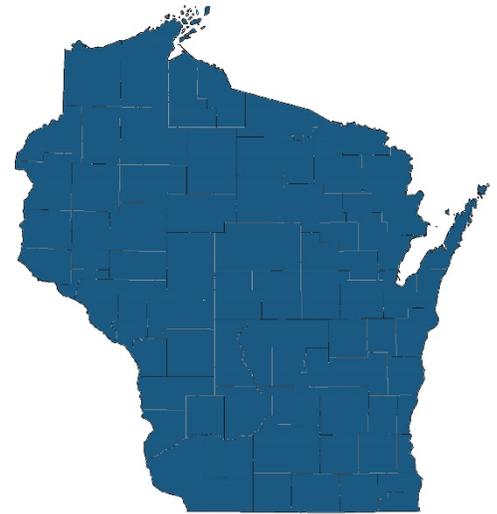
Since its launch, HealthExperiencesUSA has had tens of thousands of annual visitors to the site, and new modules, expansion of the medical school curriculum, and new applications are all underway.

New modules on HealthExperiencesUSA.org

A module on Traumatic Brain Injury in veterans, supported by the VA, is near completion. Over the next five years, numerous other modules will be launched on HealthExperiencesUSA.org, including Hereditary Cancer Risk, Pediatric Cancer, Breast Cancer, Gulf War Syndrome, and Gulf War Veterans' Health Experiences.

Adoption of the curriculum

The University of Wisconsin School of Medicine and Public Health adopted the medical student curriculum into their Year 3 Chronic and Preventative Care block. In the next four years, this curriculum will educate ~760 medical students at the university. Work is also currently underway to disseminate the curriculum nationally, which has the potential to impact ~85,000 medical students nationwide.



Current Impact

This work has implications not only for training future clinicians to address depression specifically, but also for increasing their sensitivity to diverse patients' experiences in a range of other salient areas as future modules are released.

Spreading the word

[Ebony Magazine](#) and [USA Today](#) featured the Depression in Young Adults website in articles about depression in the African American community and in relation to recent high-profile suicides.

A free toolkit to help other research teams develop patient ambassadors for health experiences research, [Engaging Research Participants in Disseminating Health Experiences Research](#), is available on HIPxChange. The toolkit contains actionable information, lessons learned, and tools and resources to create an ambassador program, plan dissemination activities with ambassadors, and evaluate their role in the dissemination activities.

Resources

Toolkit

- ✓ [Engaging Research Participants in Disseminating Health Experiences Research Toolkit](#)

Other

- ✓ All modules are freely available for use on [HealthExperiencesUSA.org](#)