Technology as a Consumer Engagement Tool to include Diverse Voices

Sarah Davis, JD, MPA

Center for Patient Partnerships
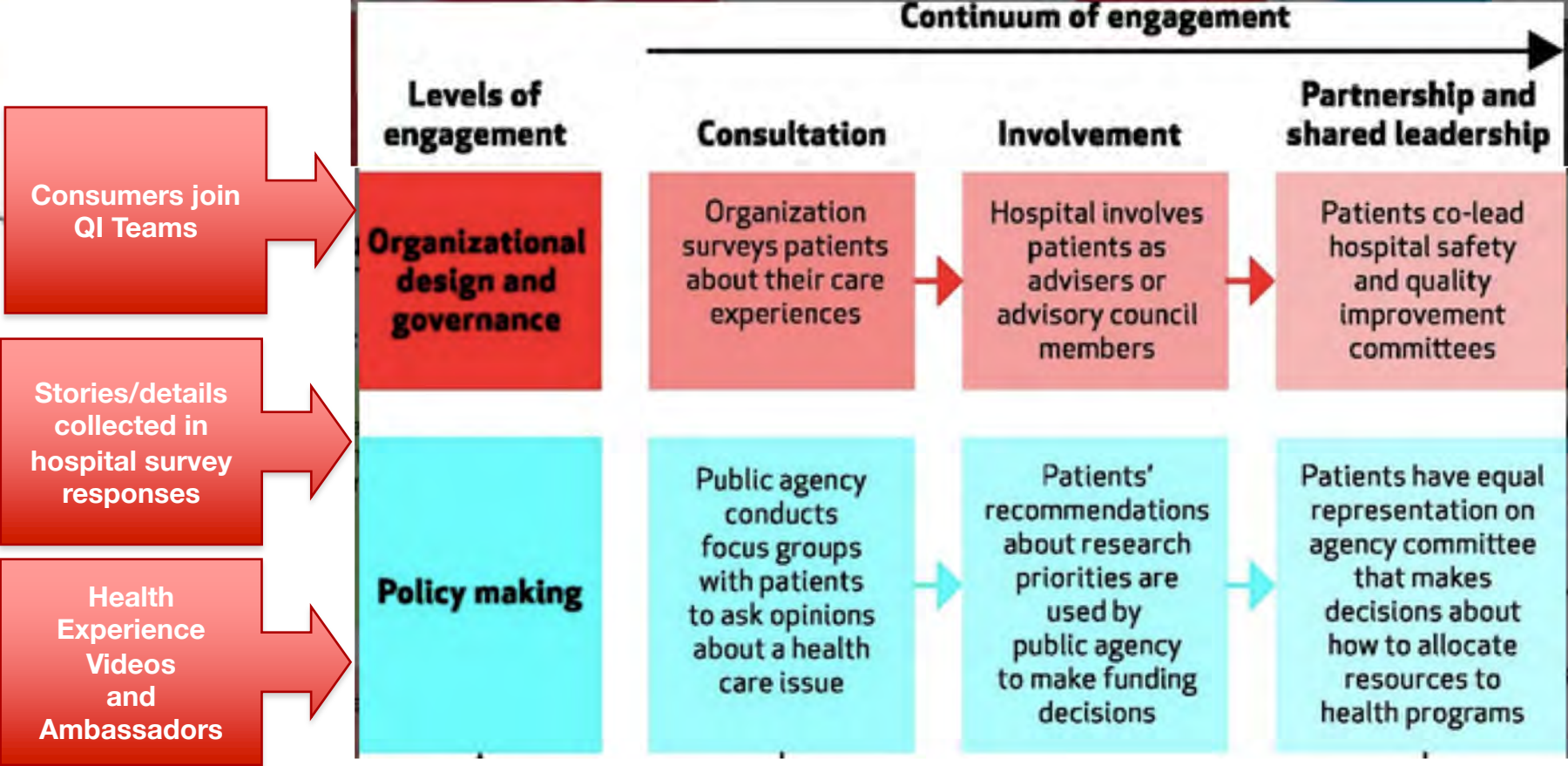
From Case to Cause

ADVOCACY

PATIENTS' EXPERIENCES

RESEARCH

SYSTEM CHANGE

EDUCATION

Center for Patient
Partnerships
University of Wisconsin-Madison

From Voice to Voices

Consumer Healthcare Engagement Points

- Self Care
- Choosing a Health Plan
- Choosing a Doctor
- Choosing Treatment Option
- Managing Medical Bills & Costs
- Advocating for System Improvement

Informed by a validated understanding of consumer needs and preferences

Advocating for System Improvement

Consumers join QI Teams

Stories/details collected in hospital survey responses

Health Experience Videos and Ambassadors

Levels of engagement	Continuum of engagement		
	Consultation	Involvement	Partnership and shared leadership
Organizational design and governance	Organization surveys patients about their care experiences	Hospital involves patients as advisers or advisory council members	Patients co-lead hospital safety and quality improvement committees
Policy making	Public agency conducts focus groups with patients to ask opinions about a health care issue	Patients' recommendations about research priorities are used by public agency to make funding decisions	Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs

Carman K, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, Sweeney J. "Patient And Family Engagement: A Framework For Understanding The Elements." Health Affairs. 2013;32(2):223–231.

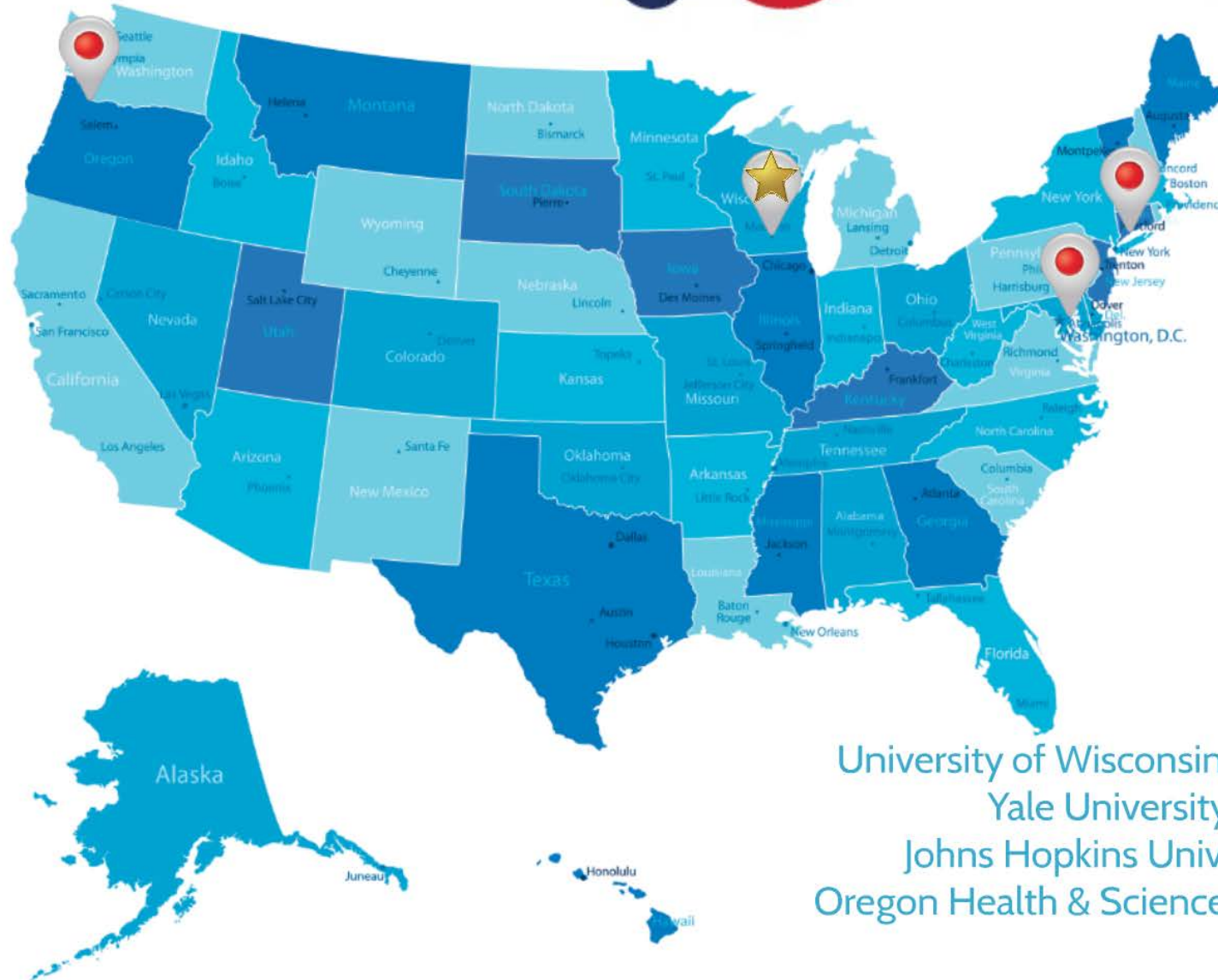# A fundamental engagement challenge: Moving beyond "the usual suspects"

Diversity of Voices

Dimensions shape:
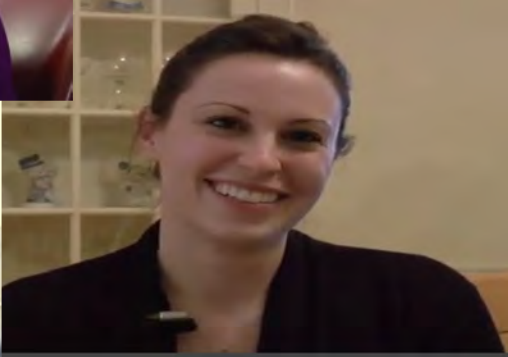
- Values
- Beliefs
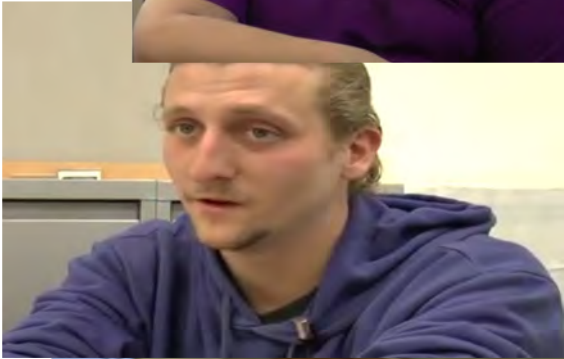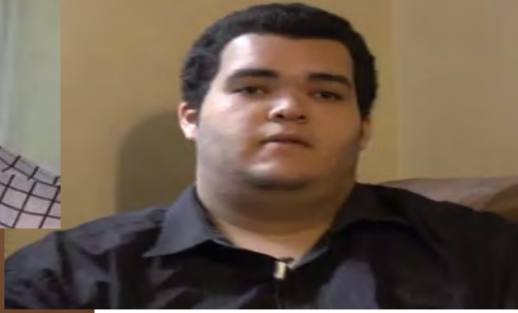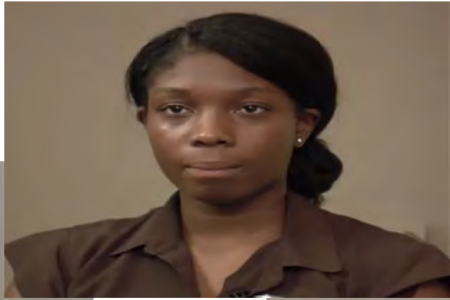- Experiences
- Expectations

Affect Health Outcomes

DIPEx USA

University of Wisconsin-Madison
Yale University
Johns Hopkins University
Oregon Health & Science University

Young Adults' Experiences of Depression in the U.S.

Topics	People's Profiles	Resources & Information	Credits

Overview

Next Topic ▶

- ▶ **First experiences with depression (2)**
- ▶ **Living with depression (19)**
- ▶ **Getting help: seeking assistance and treatment (5)**
- ▶ **Helping yourself: support, self-care, and feeling better (7)**
- ▶ **Messages to others (2)**

Overview

In this section you can find out about experiences young adults ages 18 - 29 have with depression by seeing, hearing and reading personal stories they shared with us. Our researchers travelled to several regions and many different communities throughout the United States to talk to 38 young people in their own homes or community settings. Find out what people said about issues such as growing up in the shadow of depression, dealing with combinations of depression and anxiety, deciding whether and when to "go public" with their condition, and finding strategies for everyday life or how to maintain hope as they cope with depression.

The young people who shared their stories did so for varied reasons. Their voices and personal experiences differed. But they shared a belief that speaking up and telling their stories would matter – both to themselves and to others.

EXPERIENCES OF DEPRESSION IN U.S. YOUNG ADULTS

Young adults and depression in US

PIs:
Rachel Grob, PhD
Nancy Pandhi, MD, PhD, MPH

How does Health Experiences Research enhance health care consumer engagement?

- ✓ Listening to participants to *capture a wide range of* experiences and priorities

- ✓ *Empowering participants* by giving voice to their story and choices about sharing their data

- ✓ *Bringing in and amplifying voices that wouldn't be heard* through other engagement activities

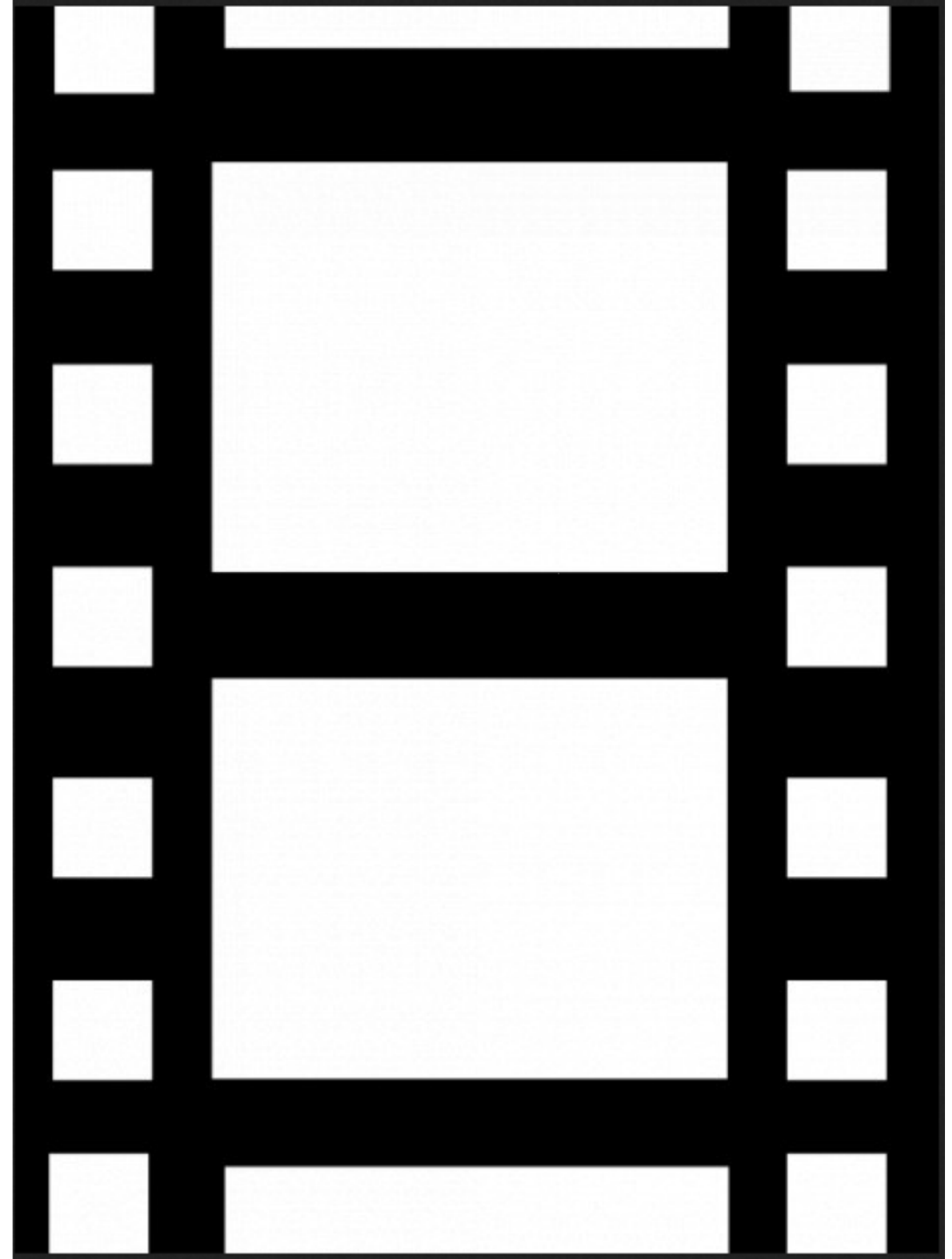- ✓ *From voice to voices – synthesizing themes and* disseminating to broad audiences– not just peer-reviewed literature

Catalyst Film

- 1 short film (under 10 minutes)
- Many voices
- Key messages

WHY USE:

- Include missing voices
- Efficient
- Can be used when consumers are not available

Video Conferencing

Social Media – Engage Consumers & Decision-Makers Online
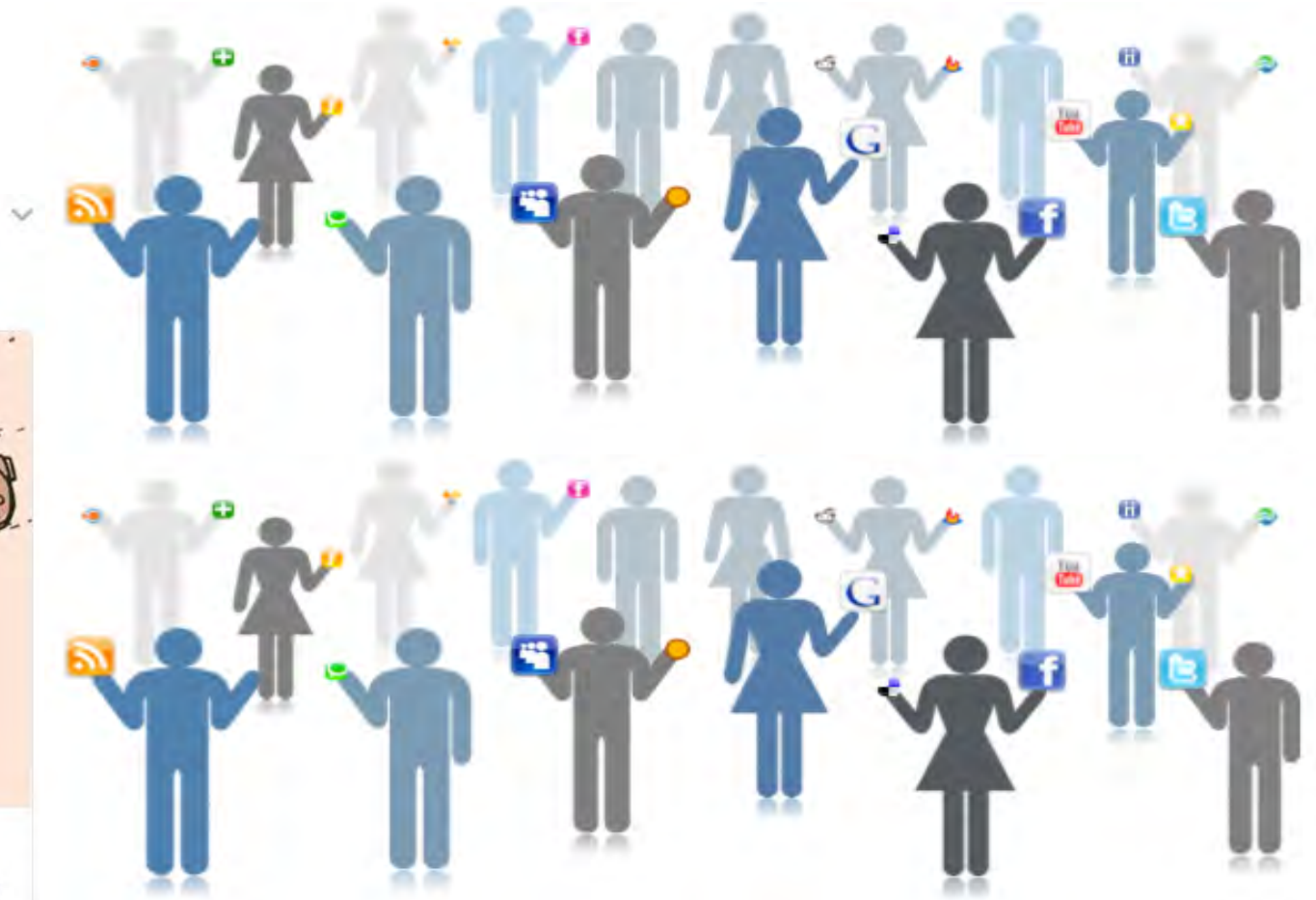

HealthExperiencesUSA @HealthExUSA · Mar 23
Fascinating piece by @amyebutcher on the student use of Yik Yak to get #depression support on college campuses:

Opinion | How the Depressed Find Solace on Yik Yak, Believe It or Not

A platform associated with the gutter of young humanity had blossomed with tenderness.

nytimes.com

Technology Inclusion Considerations

- How familiar is you audience with technology in general?

- Is the tool easy to use and intuitive?

- Is the technology transparent?

- Accessible to non-English speaking or low literacy community members?

- Can communities use it repeatedly?

- Could the use of technology further alienate or intimidate users?

Taylor, T. Plan4Health, Creating Health
Equity Through Community Engagement, American Public Health Association, February 2016. Available at:
http://www.plan4health.us/wp-content/uploads/2015/07/Plan4Health-community-engagement-webinar-2.5.16.pdf
Last Accessed: November 5, 2018.

Acknowledgements & Publications

- HealthExperiencesUSA.org

- Patient Engagement for QI Toolkit at: http://hipxchange.org/PatientEngagement

- Caplan, W., Davis, S., Kraft, S., Berkson, S., Gaines, M., Schwab, W., and Pandhi, N. "Engaging patients at the front lines of primary care redesign: Operational lessons for an effective program." *Jt Comm J Qual Saf* 2014;40(12).

- Davis, S., Berkson, S., Gaines, M. E., Prajapati, P., Schwab, W., Pandhi, N., & Edgman-Levitan, S. (2016). Implementation science workshop: engaging patients in team-based practice redesign—critical reflections on program design. *Journal of general internal medicine*, *31*(6), 688-695.

Resources

- The Point of Care Foundation. EBCD: Experience Based Co-Design Toolkit. Available at: https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/. Accessed November 5, 2018.

- Beresford, Peter. *Beyond the Usual Suspects: Towards Inclusive User Involvement: Practical Guide*. Shaping Our Lives Publications, 2013.

- Taylor, T. Plan4Health, Creating Health Equity Through Community Engagement, American Public Health Association, February 2016. Available at: http://www.plan4health.us/wp-content/uploads/2015/07/Plan4Health-community-engagement-webinar-2.5.16.pdf. Last Accessed: November 5, 2018.

- Arcia, Adriana, et al. "Sometimes more is more: iterative participatory design of infographics for engagement of community members with varying levels of health literacy." *Journal of the American Medical Informatics Association* 23.1 (2016): 174-183.

Thank You!

Sarah Davis, JD, MPA
University of Wisconsin-Madison
School of Law
School of Medicine and Public Health
➢ Sarah.davis@wisc.edu
➢ 608-265-0906