

Learning from patients' experiences: where we have been where we can go

Rachel Grob, Ph.D

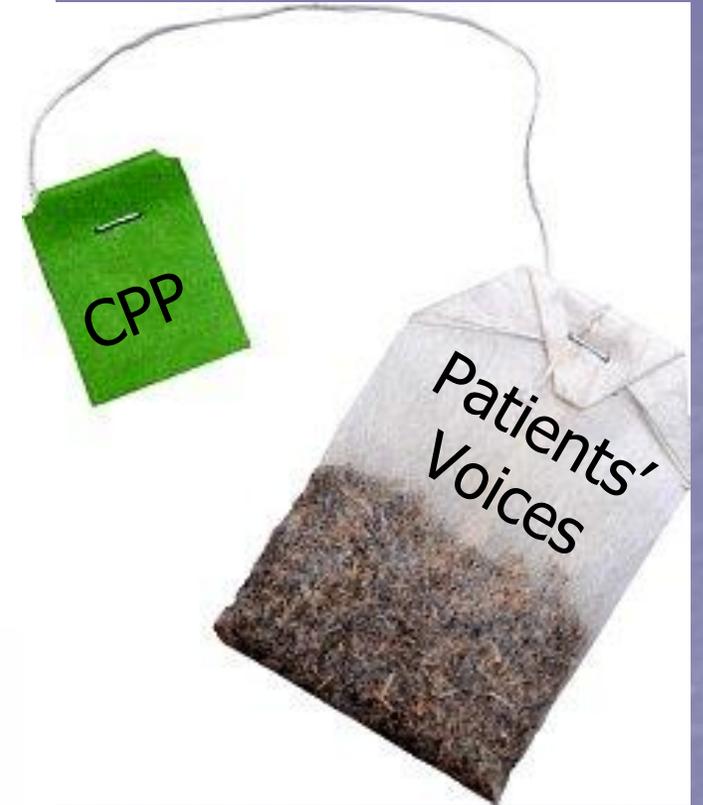
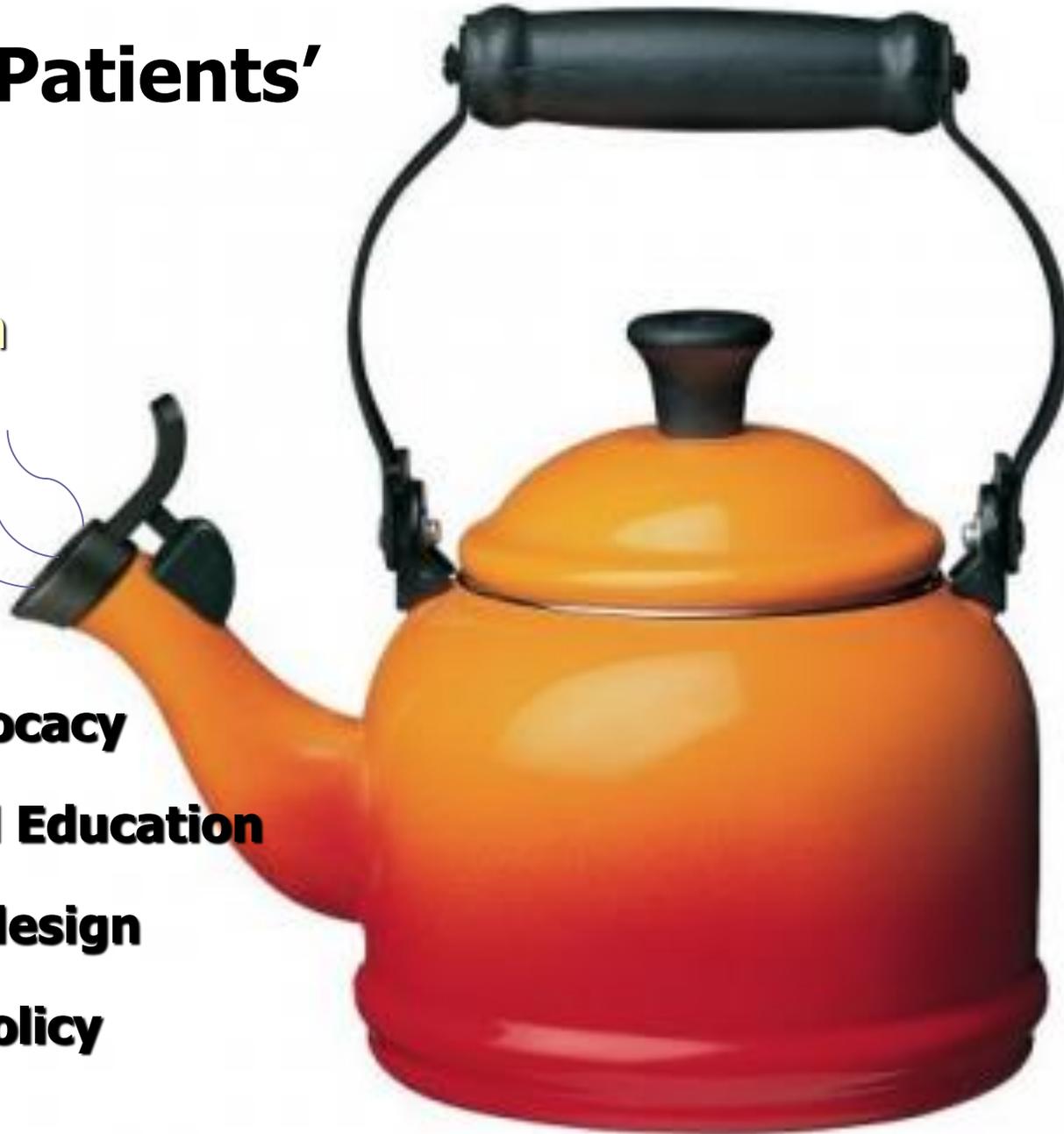
Center for Patient Partnerships, University of Wisconsin-Madison

Mark Schlesinger, Ph.D

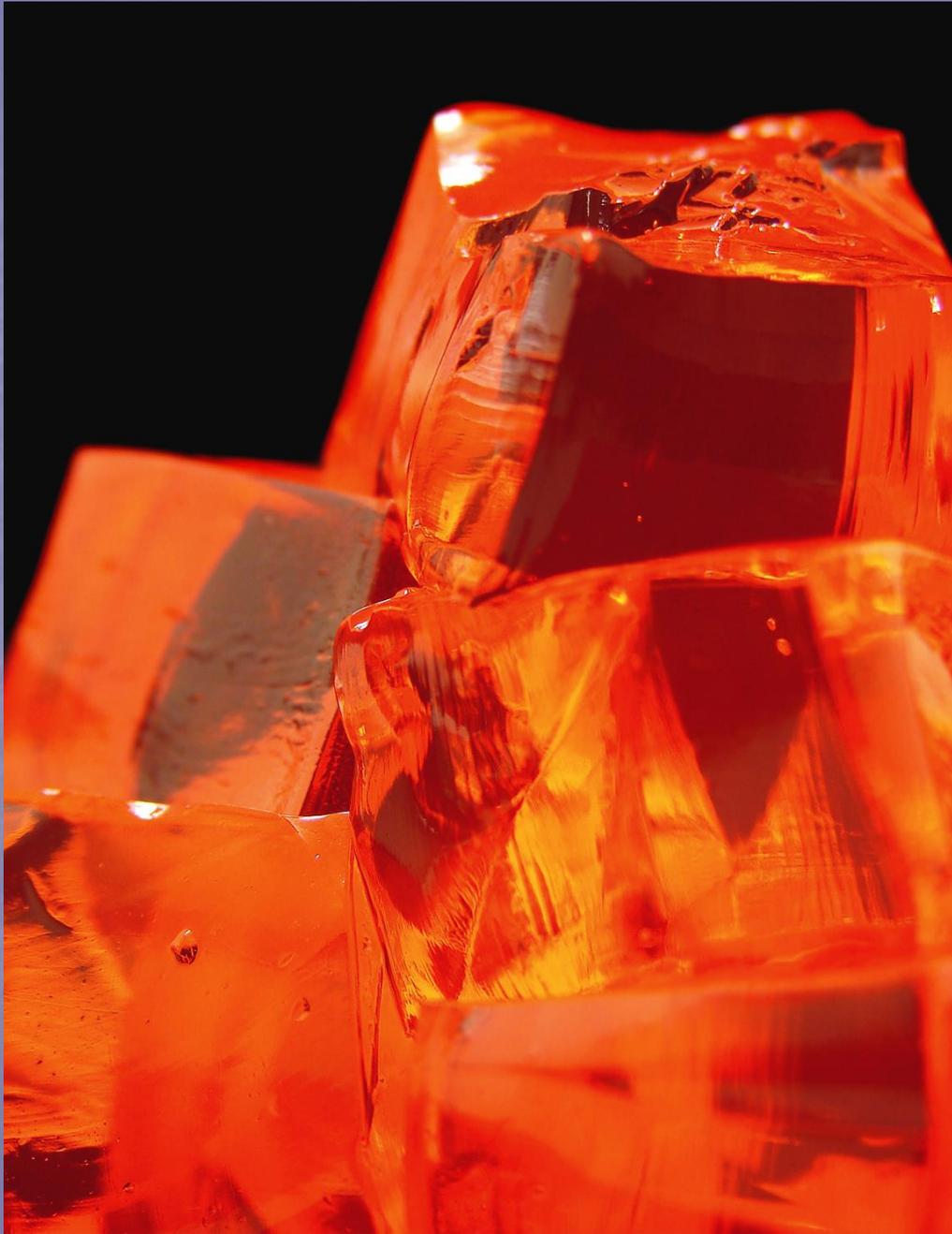
Yale University

Infusing Patients' Voices...

Better Health Outcomes



- **Patient Advocacy**
- **Professional Education**
- **Service Co-design**
- **Research/Policy Advocacy**



Your Provider

1. Our records show the provider name in the last 6 months.

Name of provider

Is that right?

- 1 Yes
- 2 No → If No

The questions in this survey are about the provider named in Question 1. Please think of that provider when you answer the survey.

2. Is this the provider you need a check-up, have a problem, or get sick?

- 1 Yes
- 2 No

3. How long have you seen this provider?

- 1 Less than 6 months
- 2 At least 6 months
- 3 At least 1 year
- 4 At least 3 years
- 5 5 years or more



How often did this provider do this in a way that was

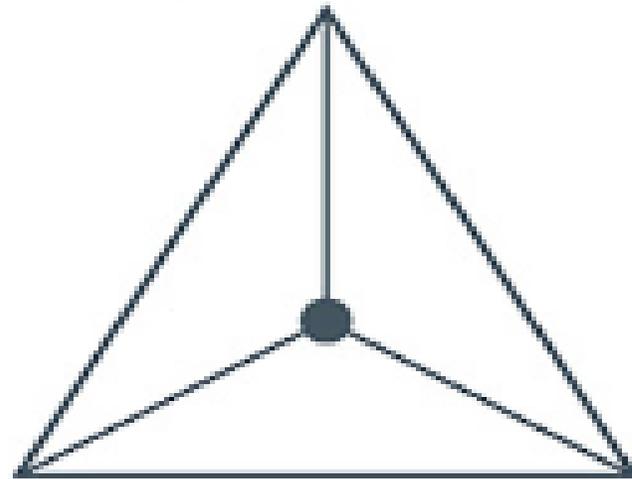
How often did this provider do this to you?

How often did this provider do this the important part of your medical history?



The IHI Triple Aim

Population Health



Experience of Care

Per Capita Cost



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2014

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Submit your manuscript today!

Journal of Patient Experience

Giving voice to our patients and our providers, the *Journal of Patient Experience (JPE)* is a peer-reviewed, open access journal published by the Association for Patient Experience.

Journal of Patient Experience (JPE) is dedicated to presenting advances and applications that impact the patient experience. It also serves as a forum to share ideas from industry leaders, caregivers, patients and family members. The blending of research, practical findings, innovation and interdisciplinary perspectives makes *Journal of Patient Experience* a valuable resource across the healthcare spectrum.

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SOUNDING BOARD

Taking Patients' Narratives about Clinicians from Anecdote to Science

Mark Schlesinger, Ph.D., Rachel Grob, Ph.D., Dale Shaller, M.P.A., Steven C. Martino, Ph.D.,
Andrew M. Parker, Ph.D., Melissa L. Finucane, Ph.D., Jennifer L. Cerully, Ph.D.,
and Lise Rybowski, M.B.A.

- Definition of rigor in the move from anecdote to science:
 - Sampling
 - Elicitation
 - Interpretation

Eliciting Patient Narratives in American Medicine

**Applying Rigorous Qualitative Methods
to Large-Scale Collection of Patient Experience**

Eliciting Patient Narratives at Large-Scale

➤ **Laying the Groundwork**

- Developing criteria for rigor
- Several rounds of elicitations
- Matched interviews for validation

Eliciting Patient Narratives at Large-Scale

➤ **Laying the Groundwork**

- Developing criteria for rigor → 4 criteria
- Several rounds of elicitations
- Matched interviews for validation

Criteria for Rigorous Elicitation

- ***Complete***: provide a full picture of the experiences that matter to the patient describing them
- ***Balanced***: accurately reflect both positive and negative aspects of the patient's experiences
- ***Meaningful***: convey a story that is coherent to other patients and allows them to assess its relevance to their own care
- ***Representative***: Capture experiences from patients across a range of health status and socio-demographics

Eliciting Patient Narratives at Large-Scale

➤ Laying the Foundation

- Developing criteria for rigor
- Several rounds of elicitations → 758 cases
- Matched interviews for validation

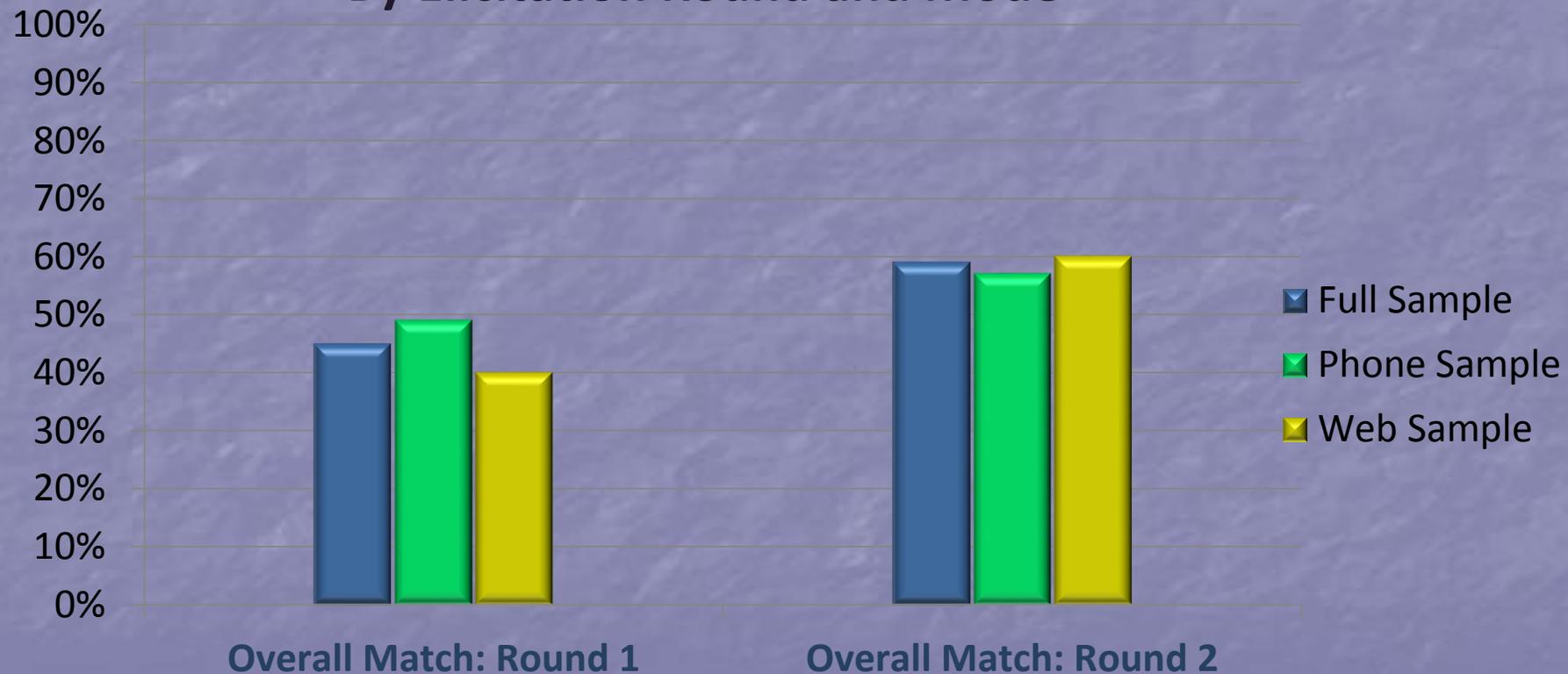
Eliciting Patient Narratives at Large-Scale

➤ **Laying the Foundation**

- Developing criteria for rigor
- Several rounds of elicitations → 758 cases
- Matched interviews for validation → 100 cases

Testing (and Refining) the Protocol

COMPLETENESS of Reported Experiences By Elicitation Round and Mode



Eliciting Patient Narratives at Large-Scale

➤ **Laying the Foundation**

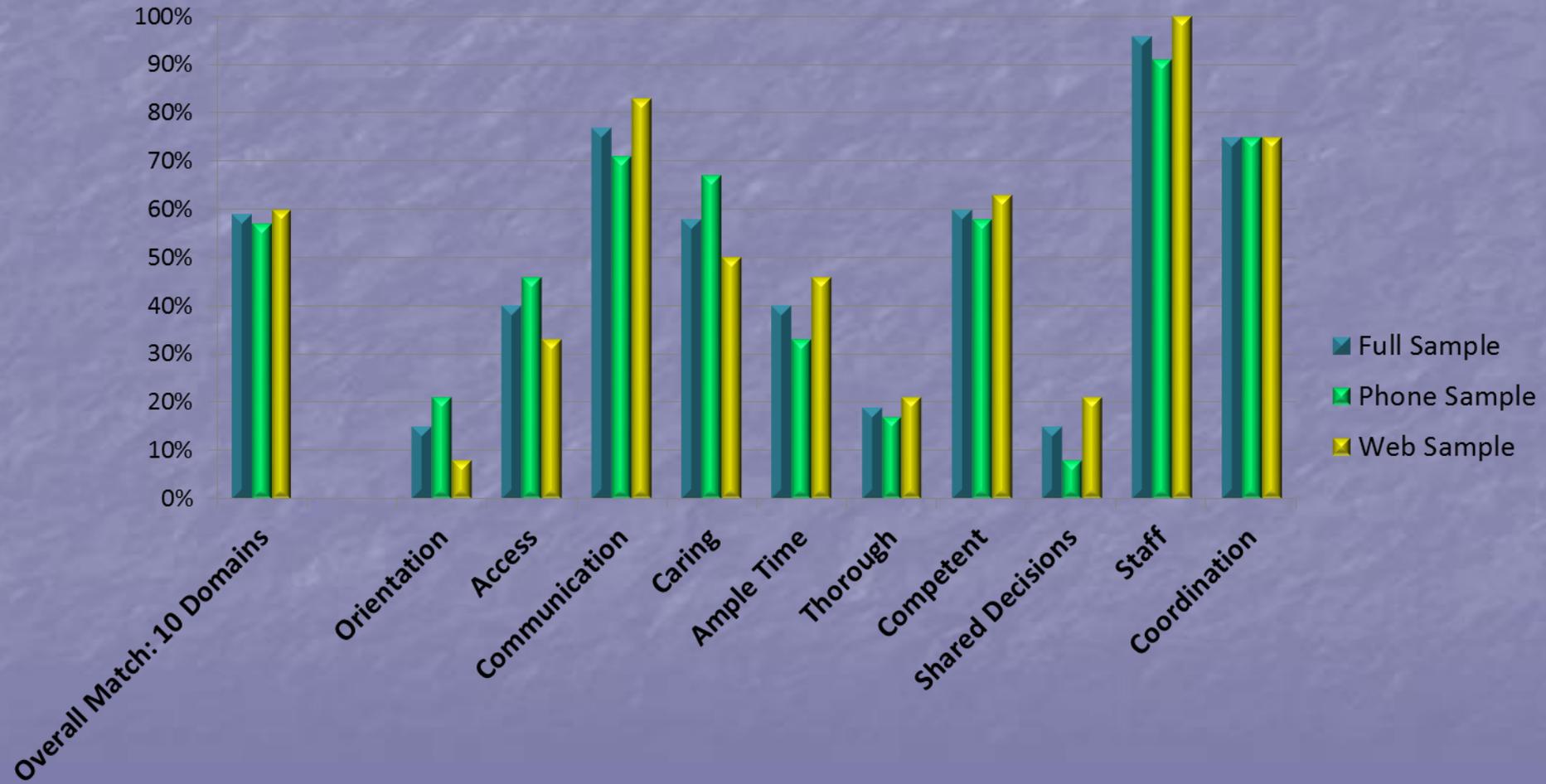
- Developing criteria for rigor
- Several rounds of elicitations
- Matched interviews for validation

➤ **Evaluation**

- Complete

Completeness of Elicitation

Fidelity of Reported Experiences



Eliciting Patient Narratives at Large-Scale

➤ **Laying the Foundation**

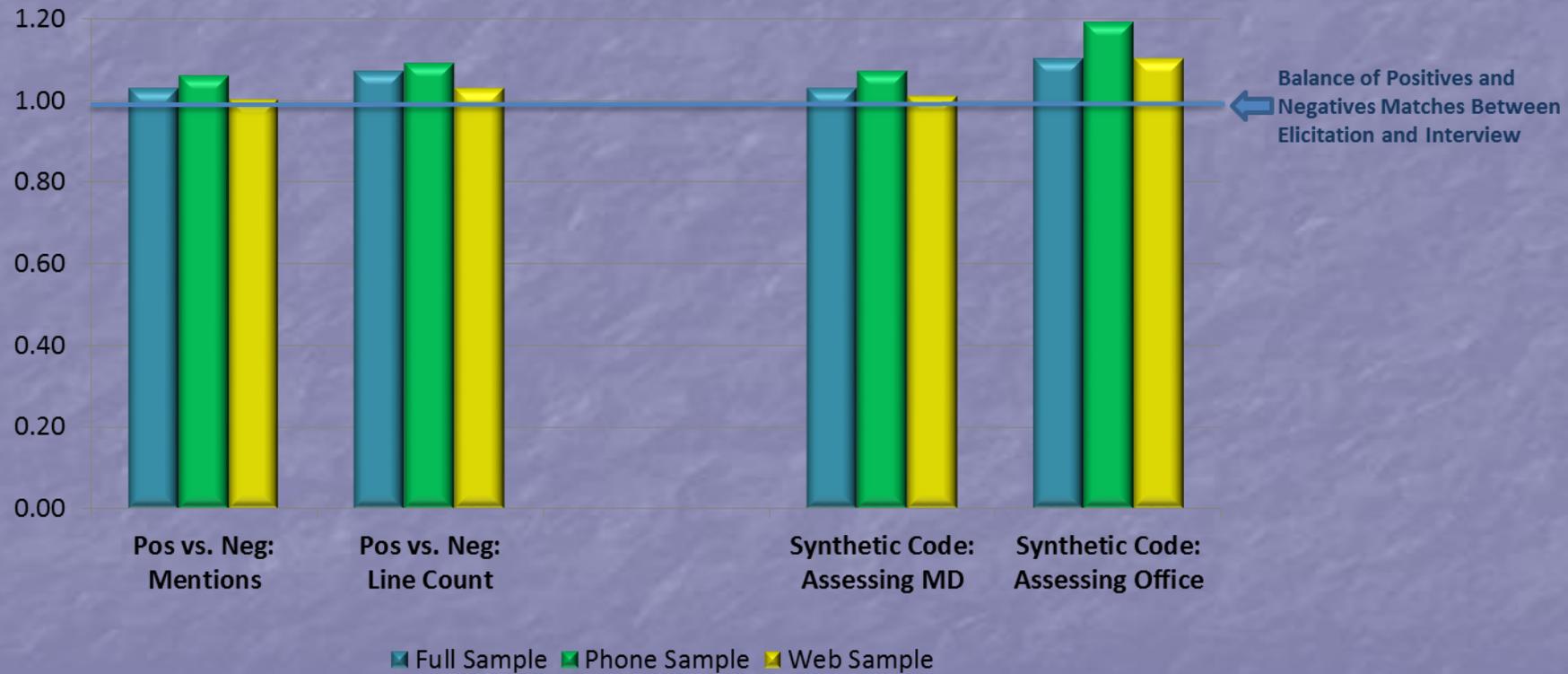
- Developing criteria for rigor
- Several rounds of elicitations
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➤ **Evaluation**

- Balanced

Balance of Elicitation

Fidelity of Positive vs. Negative Assessments



Eliciting Patient Narratives at Large-Scale

➤ **Laying the Foundation**

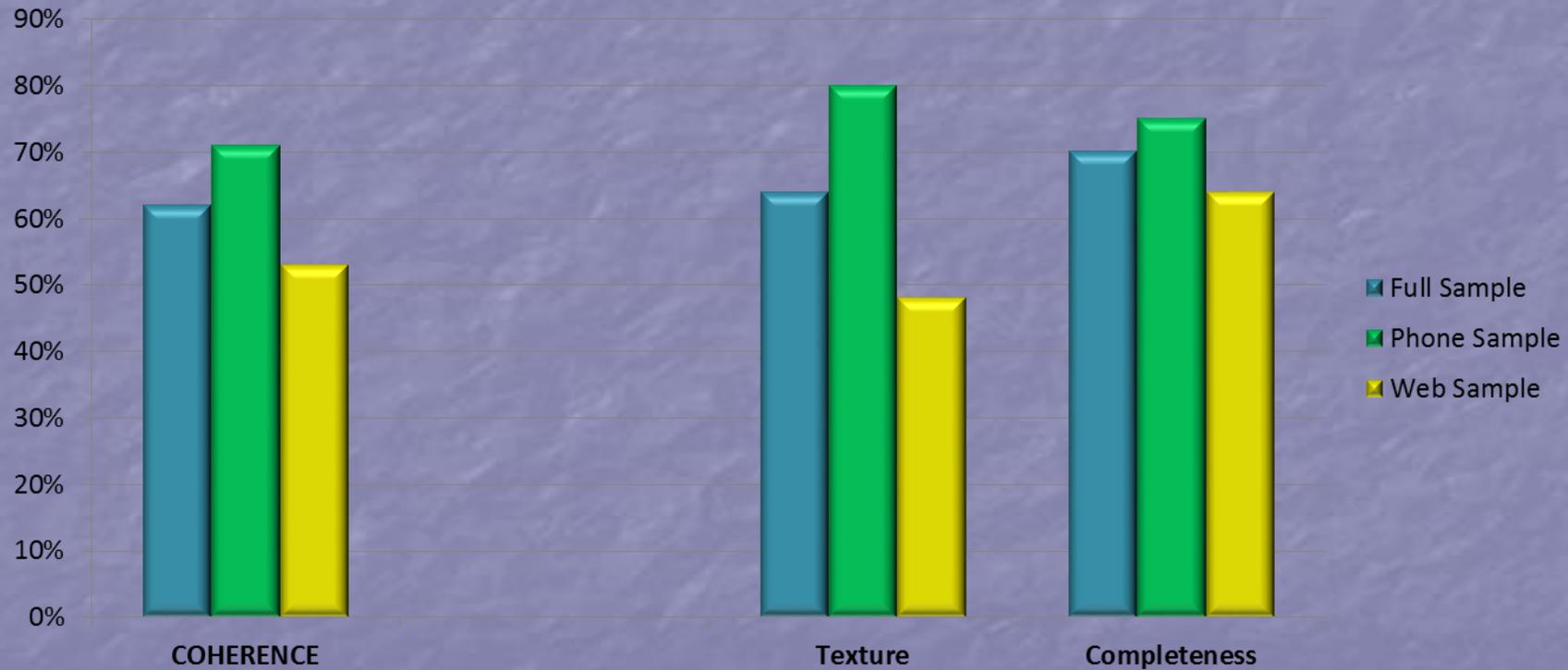
- Developing criteria for rigor
- Several rounds of elicitations
- Matched interviews for validation

➤ **Evaluation**

- Meaningful

Coherence of Elicitation

Attributes of the Narratives



Eliciting Patient Narratives at Large-Scale

➤ **Laying the Foundation**

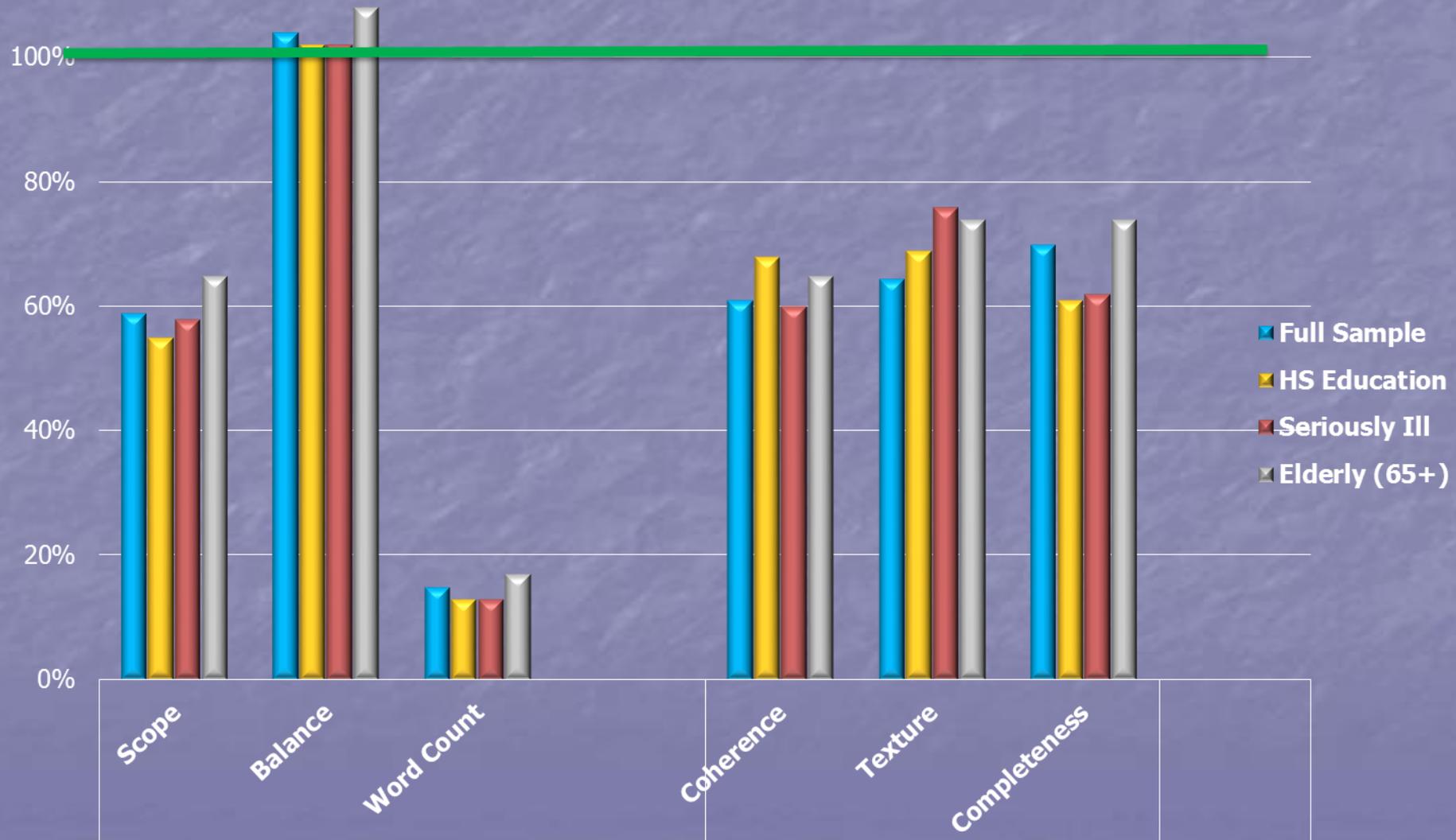
- Developing criteria for rigor
- Several rounds of elicitations
- Matched interviews for validation

➤ **Evaluation**

- Representative

Representativeness of Elicitation

Elicitation Performance by Subsets of Respondents



Eliciting Patient Narratives at Large-Scale

- **Laying the Foundation**
- **Evaluation**
- **Dissemination**
 - **Pilot-testing: CA and MA**
 - **Initial Implementation: MA**

A Database of Patient Experience: Eliciting Rich Narratives about Health and Health Care



Why DIPEX?

- Identify questions and problems that matter to patients
- Provide support and information to patients and caregivers
- Promote balanced encounter between patients and health professionals
- Be a learning resource for medical students, doctors, nurses and other health professionals
- Inform policy



DIPEX methodology

- Aim is to represent the broadest possible range of perspectives, *using rigorous qualitative research methods*
- For each health condition (or module), researchers conduct 40 - 50 interviews, among patients from different backgrounds, recruited through a range of avenues (maximum variation)
- Interviews continue until no new ideas or experiences are voiced (saturation)

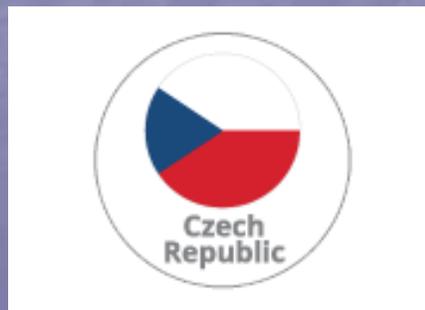
DIPEX methodology

- Transcripts coded by theme, with focus on both common and divergent experiences
- Researchers produce ~ 35 summaries in lay language, illustrated with video, audio, or written interviews clips (roughly 350 clips per module)
- Modules disseminated via publicly-available website (e.g. www.healthtalk.org); data available for secondary analysis and use (with permission)



DIPEX International

www.dipexinternational.com





Health Experiences Research Network

healthexperiencesusa.org



Partnership between University of Wisconsin, Johns Hopkins University, Oregon Health & Science University, and Yale University.

Health Experiences Research Network (HERN) Steering Committee

Launched in in 2014

Rachel Grob, MA, PhD
Chair

Erika Cottrell, PhD, MPP
Kay Dickersin, PhD
Mark Helfand, MD, MPH
Kate Smith, PhD, MA
Nancy Pandhi, MD, PhD
Mark Schlesinger, PhD



US Health Experiences Modules

Two funded modules

- ✓ Depression in young adults (UW-Madison)
- ✓ Veterans with traumatic brain injury (VA/OHSU)

Proposed modules under review

- Gulf War Illness (VA)
- Pediatric cancer (NIH CTSA)
- Adults with congenital heart disease (NIH CTSA)
- Low back pain (Donaghue Foundation)



HERN's commitment is to:

- ✓ Listen to patients to *capture a wide range of* experiences and priorities
- ✓ *Empower patients* by giving voice to their story and choices about sharing their data
- ✓ *Bring in voices that wouldn't be heard* through other engagement activities
- ✓ *Move from voice to voices – synthesizing themes and* disseminating to broad audiences– not just peer-reviewed literature



US Module: Young Adults with Depression



US Module: Young Adults with Depression

Study Team

Rachel Grob, MA, PhD

Nancy Pandhi, MD, MPH, PhD

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Mark Schlesinger, PhD

Natalie Wietfeldt, BA

Cecie Culp, MPA

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- The Center for Patient Partnerships
- University of Wisconsin Department of Family Medicine and Community Health
- University of Wisconsin-Madison Health Innovation Program



Young adulthood: A critical time of change



Our Recruitment Flyer



Talking about
depression



**TELL YOUR
STORY
TO HELP
OTHERS.
FEEL LESS
ALONE.**

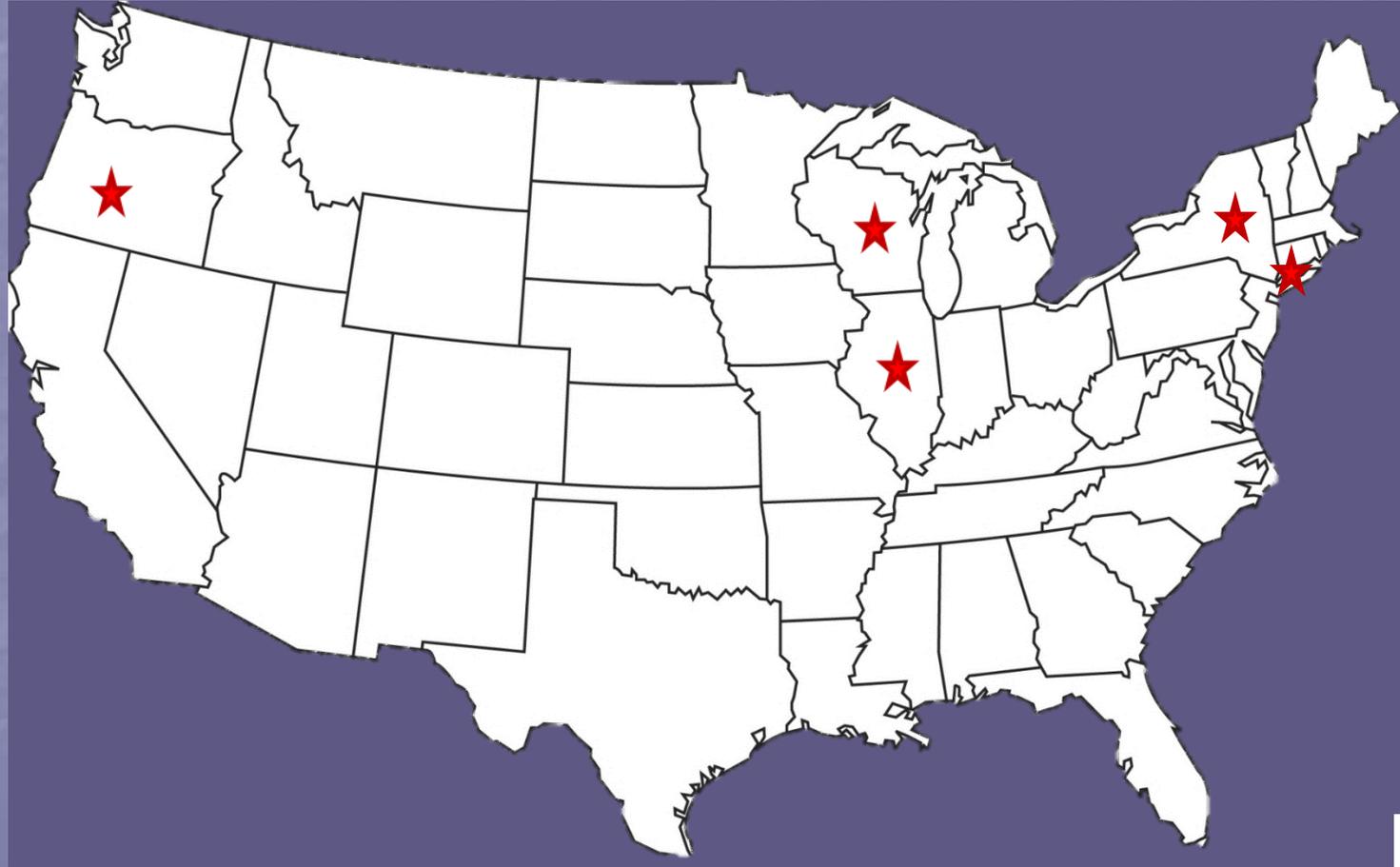


As part of a new project, researchers in the Department of Family Medicine at the University of Wisconsin are trying to find young adults (ages 18-29) interested in sharing their experiences of having depression. The project's goal is to create a module on a website with information for individuals and their caregivers about others' personal experiences living with depression. You will be compensated \$25 for participating. Please call or contact us via text (608-285-2078) or email (healthtalkus@gmail.com) if you are interested.

healthtalkus@gmail.com
Call or Text: 608-285-2078



Where we've Interviewed



Live Depression Module

www.healthexperiencesusa.org

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

Topics	People's Profiles	Resources & Information	Credits
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Overview

▼ First experiences with depression (2)

Depression and feeling different when young

Young adults' views about what causes depression

► Living with depression (19)

▼ Getting help: seeking assistance and treatment (5)

Getting professional help for depression

Therapy and counseling

Depression, medication, and treatment choices

Depression treatment in emergency rooms and hospitals

Holistic and integrative approaches to depression

▼ Helping yourself: support, self-care, and feeling better (7)

Having a purpose in life

Building relationships that work when depressed

Depression and pets

Depression and strategies for everyday life

Cycles of depression and maintaining hope

Depression, spirituality, and faith

Depression and healing

▼ Messages to others (2)

Messages to family and friends: how to support a person with depression

Messages to other young adults with depression

Next Topic ►



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.



EXPERIENCES OF DEPRESSION IN U.S. YOUNG ADULTS

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.



Young adults who told their stories for this website also wanted to be sure to remind visitors to the website like you that if at any time you need immediate crisis assistance, help is available. Please visit our [resources](#) for more information.

Dr. David Rakel of the University of Wisconsin, provides some background on these experiences and offers ideas for how to explore this content.



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)**

How depression feels

Signs and symptoms of depression

Depression and eating disorders

Depression and anxiety

Depression and obsessive compulsive disorder (OCD)

Depression, substance use and abuse

Depression and self-harming

Going public with depression?

Depression and abuse

Depression and identity

Depression and relationships

Depression and school

Depression and everyday tasks

Depression and work

Depression, bias, and disadvantage

Barriers to care

The positive sides of depression

Depression and suicide

Depression and transitions to adulthood

▶ **Getting help: seeking assistance and treatment (5)**

▶ **Helping yourself: support, self-care, and feeling better (7)**

▶ **Messages to others (2)**

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▼ [First experiences with depression \(2\)](#)

Depression and feeling different when young

Young adults' views about what causes depression

▼ [Living with depression \(18\)](#)

How depression feels

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▼ [Helping yourself: support, self-care, and feeling better \(7\)](#)

Having a purpose in life

Building relationships that work when depressed

Depression and pets

Depression and strategies for everyday life

Cycles of depression and maintaining hope

How depression feels

In the United States, clinical guidelines and/or DSM-V Criteria describe specific signs and symptoms professionals can use to diagnose depression*. In this section of the website, we focus on something different: how depression feels to young adults while they are living inside of it, as described by those we interviewed. (For summaries of how it feels for young adults to cycle in and out of depression, or how it feels to be healing from it, see ["Cycles of depression and maintaining hope"](#) and ["Depression and healing."](#))

Young adults have a variety of experiences with depression, but one thing all those we talked to shared is the feeling that they are somehow separated from the rest of the world. Each person described, in one way or another, being in their "own little world," losing their motivation to do things, and becoming socially isolated. One person talked about "feeling so alien to the rest of the world around me." Sam said that when he's depressed he has to "unplug and not really communicate with anyone."



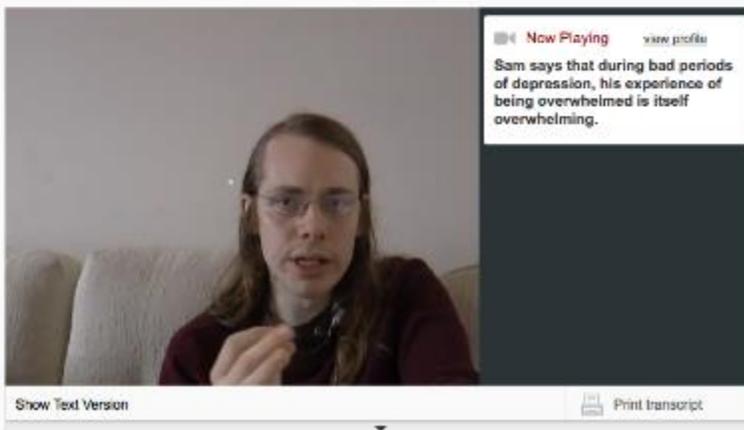
Now Playing [view profile](#)

Marty describes how he could not get out of bed.

00:08 00:21

Show Text Version [Print transcript](#)

For many people, that sense of isolation was accompanied by feeling overwhelmed. Some described this as everything becoming unmanageably "abrasive to my senses": bright lights, groups of other people, noise, daylight. Others talked about everyday responsibilities like school work becoming "frightening," or dissolving in tears while in public without knowing why.



Now Playing [view profile](#)

Sam says that during bad periods of depression, his experience of being overwhelmed is itself overwhelming.

Show Text Version [Print transcript](#)

Metaphors about depression

For many of those we interviewed, ordinary language and descriptions were not nuanced enough to



▼ **First experiences with depression (2)**

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Depression, spirituality, and faith

Depression and health

Depression and work

Many young adults between the ages of 18 and 29 have not yet had time to develop a long or diverse work history, regardless of whether they are depressed. Nonetheless, most people we interviewed talked about the impact depression had on their experiences with work, and/or about how work influenced their depression. Some also described how and whether they "went public" with their depression in professional environments, or what role income (or its absence) played in their lives.

Work making depression easier

A number of people described how work functions as an effective antidote to feelings of isolation, powerlessness, or low self-esteem that accompany depression. For some, being busy with work and "having a routine" as well as needed income was a tremendous help: as Meghan put it, "busy people are organized people and [having a campus job] has helped a lot... just being committed to something [and]... having a schedule that I can maintain." Other people talked about work as a "productive distraction" which provides relief from endlessly "thinking about how I'm feeling." Marty used his job to practice "step[ing up] and being a leader."



Now Playing [view profile](#)
Joey says getting even a "crappy" job added necessary structure to his life and immediately made him less depressed.

[view profile](#)
For Jacob, having a job creates a positive feedback loop: interacting with others lessens his depression, which in turn creates more motivation to excel at work, which lessens depression yet more.

Show Text Version

Print transcript

A few people mentioned how the substantive focus of their work or the specific requirements of their job challenged them to move through symptoms of depression by making it necessary to "come out of my shell" or to be intensely "emotionally aware" of self and others. The opportunity that work creates to meet and spend time with other people was highlighted by several people as particularly meaningful.



Text only
Read below

Now Playing [view profile](#)
Colin's job gives him the chance to be "part of something" with other people.

Show Text Version

Print transcript

The friends I met now I've met through my job, I work at a dining hall. I got promoted, I applied for the promotion, I'm a supervisor there.

Profile Info [view profile](#)

Age at interview: 20

Sex:



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

Topics	People's Profiles	Resources & Information	Credits
<ul style="list-style-type: none">▶ Men age 18-20 (3)▶ Women age 18-20 (5)▶ Men 21-24 (6)▶ Women 21-24 (8)▼ Men 25 and over (7) <p>Pete</p> <p>Marty</p> <p>Joey</p> <p>Jason</p> <p>Jacob</p> <p>Jackson</p> <p>Ben</p> <ul style="list-style-type: none">▶ Women 25 and over (9)	<h3>Men 25 and over</h3> <div><p>Pete</p><p>Pete's depression became noticeable as a young adult, but looking back he thinks he had...</p></div> <div><p>Marty</p><p>Marty has struggled with depression, anxiety, and other issues since childhood. He has...</p></div> <div><p>Joey</p><p>Joey had some extended periods of low mood earlier in his life, but the first time he...</p></div> <div><p>Jason</p><p>Jason's first serious bout of depression happened once he was away at college, but looking...</p></div> <div><p>Jacob</p><p>Jacob, 25, noticed symptoms in early high school and was diagnosed with depression and...</p></div> <div><p>Jackson</p><p>Jackson, 27, experienced childhood abuse, father's suicide and mother's imprisonment...</p></div> <div><p>Ben</p><p>Ben's depression began when he was 13. He was diagnosed with depression and schizophrenia...</p></div>		



Empowering patients by giving voice to their story and control over how it is shared

- Ongoing communication to review and approve materials
 - Feeling seen
 - Redacting materials
- Ongoing engagement:
 - e-mail
 - Advisory Group
 - Sampling
 - Topic Summaries
 - Bios



Bringing in voices that wouldn't be heard through other engagement activities

For example, engaging quiet and diverse voices



“... many of the most important institutions of contemporary life are designed for those who enjoy group projects and high levels of stimulation...”



... and Helping Every Voice be Heard

Amplifying patients' voices



Maya



"One of the things that I wanted to share in this interview was the fact that I think so often we are talking about depression and anxiety as though it's only a negative . . . But you know, we all have these different ranges. I'm a person when it comes to like, the analogy about a piano, I play all the keys. I have very high highs and I have very low lows."



Natasha

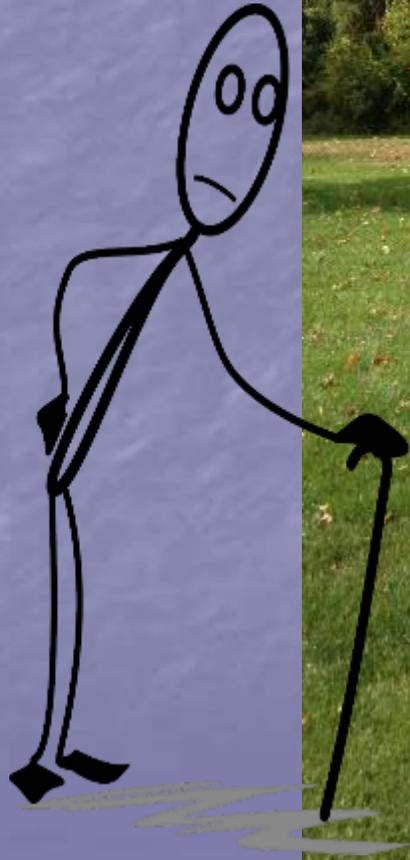


"[Depression,] it's sort of always a journey, that's a cliché statement but it's sort of a constant thing that you have to deal with . . . [it's] a journey that I'm getting more comfortable with, like easier to navigate. I guess my situation is really unique, coming from this super small place and also being a queer person is interesting, I thought that would be a voice that would be good to have."



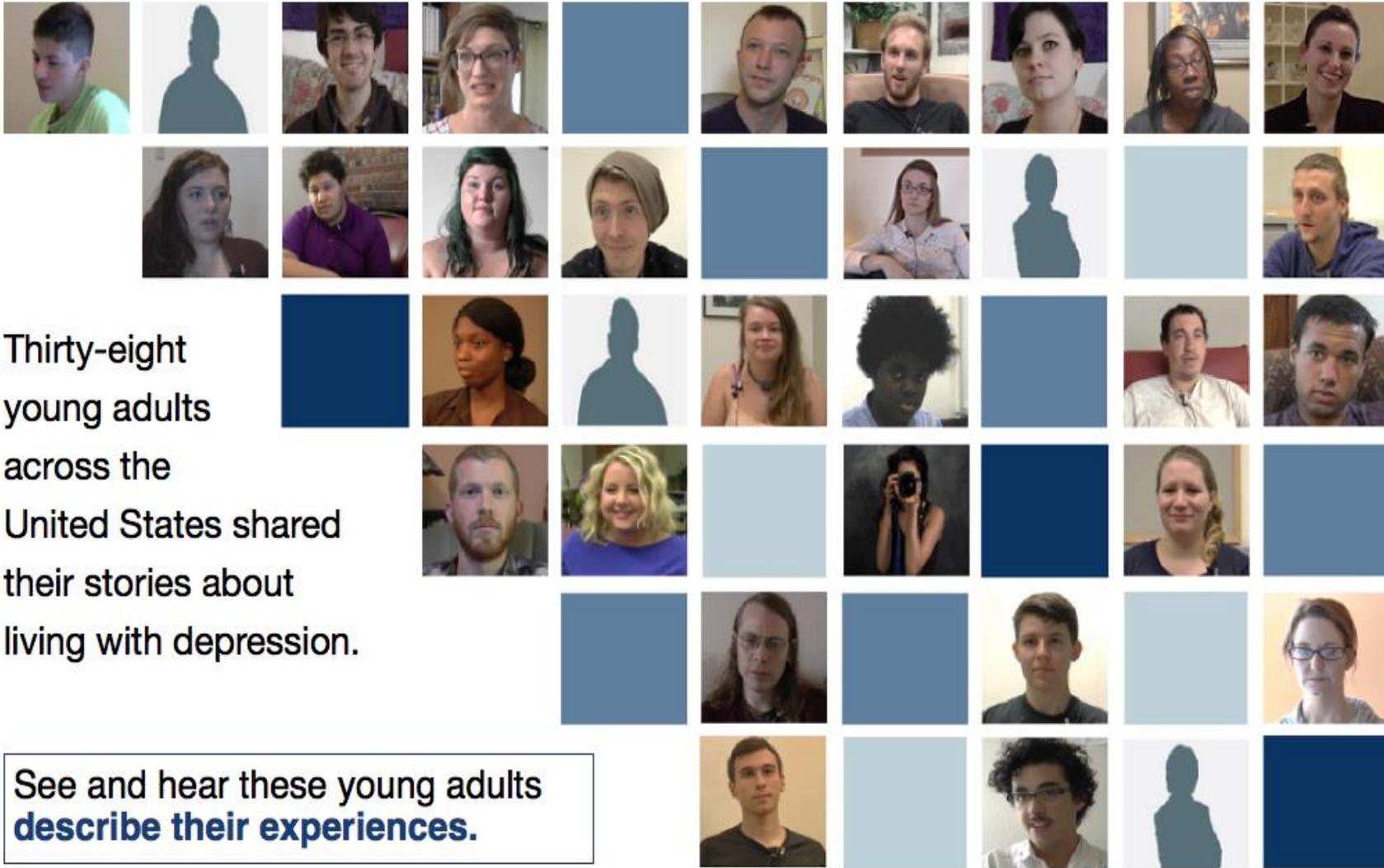
*From
Voice*

....



.....to Voices

Young Adults' Experiences With Depression



Thirty-eight young adults across the United States shared their stories about living with depression.

See and hear these young adults **describe their experiences.**



 **healthexperiencesusa.org**

Oh, the Places
You'll
Go!



By
Dr. Seuss

Your Questions?