

# UNDERSTANDING HEALTH EXPERIENCES AND VALUES IN ORDER TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

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Portland, Oregon — April 22-25, 2017



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*"Patients pay our paychecks. We are not here for ourselves. We need to have an overall vision that we are here for the patients"*

-UW Health receptionist

# From visiting patients to clinic visits



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# Caring for diverse people



[http://web.jhu.edu/dlc/resources/diversity\\_wheel/index.html](http://web.jhu.edu/dlc/resources/diversity_wheel/index.html)





# Bringing People & Systems together: Participatory Action/User Design

- Design around peoples' needs & requirements
  - Immersing/observing/understanding their **context**
  - **Engaging** community in offering ideas and priorities



# Example 1: Health Experiences Research Network Young Adults with Depression Module



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# Bringing the Database of Individual Patient Experiences (DIPEx) approach to the US...

- Systematic collection of peoples' diverse stories about the experience of an illness
- Synthesized and disseminated both through scholarly papers and a multi-media website



# Recruitment aim: represent broadest range of perspectives



Talking about  
depression



WISCONSIN  
UNIVERSITY OF WISCONSIN-MADISON

**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.

craigslist

post to classifieds

my account

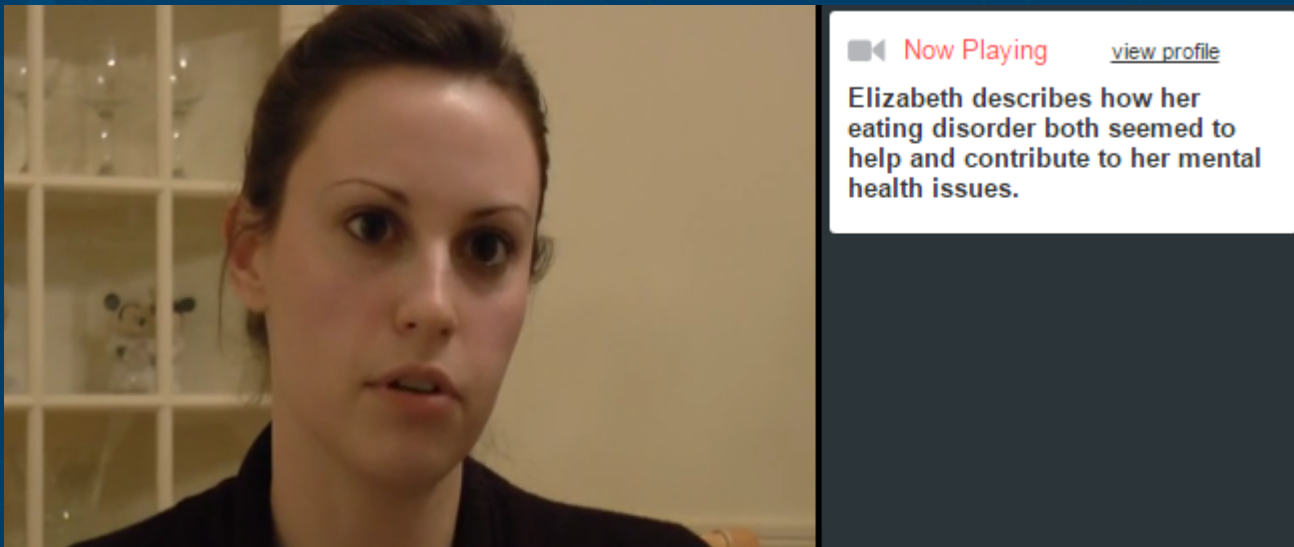
jobs

[ETC]

[ part-time ]



# Interviews in home or participant preferred setting



<http://www.healthtalk.org/peoples-experiences/mental-health/young-adults-experiences-depression-us/depression-and-eating-disorders>



# Participants have control of what is shared and how it is shared.....

I have reviewed my transcript and have crossed out any material that I wish to exclude. With the exception of those sections that I crossed out, I consent to my interview being available in the following format(s):

Check all that apply:

- ☐ Video recording of interview
- ☐ Audio recording of interview
- ☐ Written transcript of interview

I understand that my interview will only be used in the manner set out above. If I decide that I no longer want my interview to be used on the website (or for any other purpose) it will be removed, although I accept that it may not be possible to remove all existing copies from circulation.

**Name:** (block capitals) \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

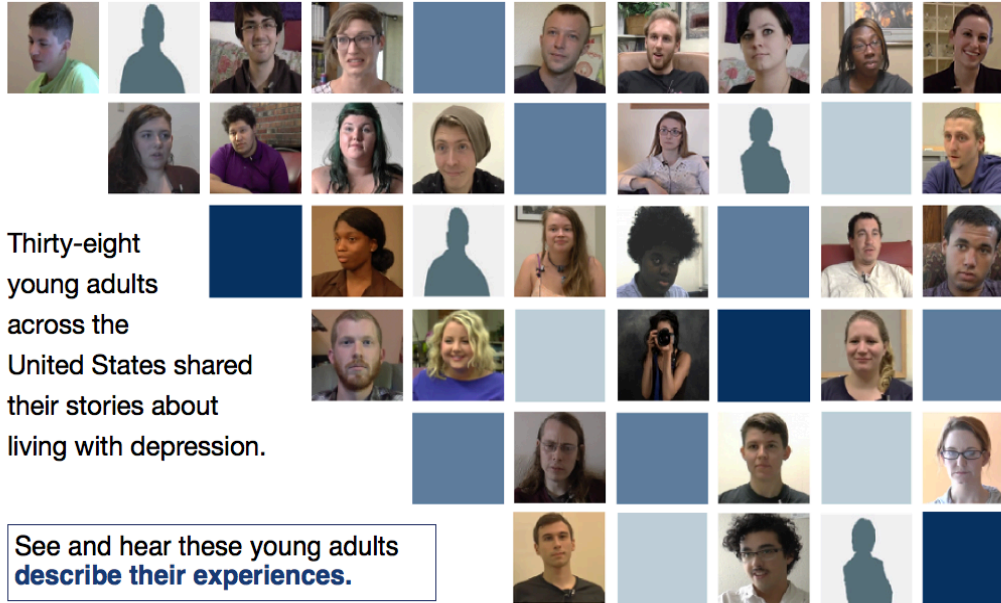
# Ongoing participant engagement (if desired)

- Regular communication to review and approve materials
- More substantive engagement:
  - Advisory Group
  - Ambassadors



# Moving 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.**

# Resource at healthexperiencesusa.org

**People's Experiences** Mental health > Young Adults' Experiences of Depression in the U.S. > Topics




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


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.

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**

# Resource at [healthexperiencesusa.org](http://healthexperiencesusa.org)

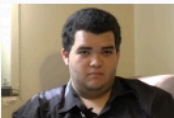





## Overview

- ▶ **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)**



# Resource at [healthexperiencesusa.org](http://healthexperiencesusa.org)

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

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



## Example 2: Dane 1 in 4



# Creating Video Vignettes Depicting Models of Integrated Behavioral Health



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# Three simple questions

**7. If you were this patient, what would you like about getting care in this way?**

**8. What would you not like?**

**9. What would you want to be different in your life after this visit?**

# Community, clinic and online surveying (N=381)



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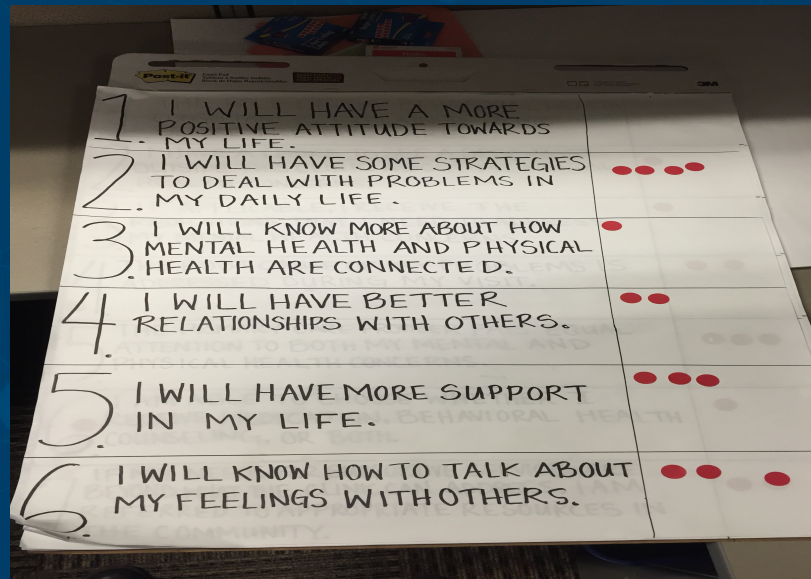
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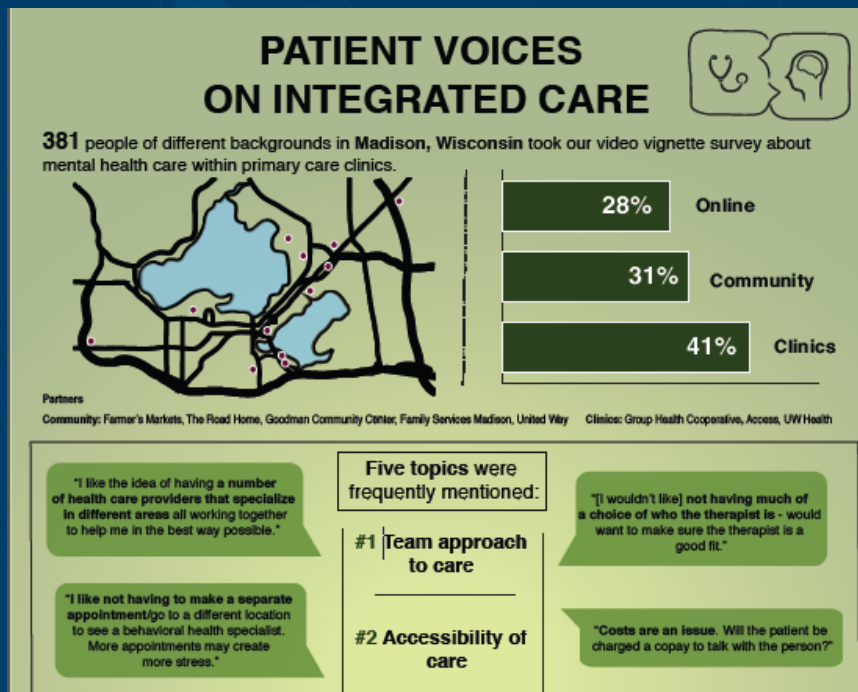
# Outcome prioritization

Items categorized by the following themes were ranked:

- Care experience
- Well-being
- Dignity
- Access/Services



# Sharing results back



<http://www.dane1in4.org/?q=node/90>



# In conclusion...



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