

Harnessing High Touch and High Tech: Combining Traditional Engagement and Social Media to Maximize Dissemination

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Learning Objectives

- Design a stakeholder-engaged dissemination plan that maximizes the potential for implementation and sustainability
- Identify barriers to effective dissemination and ways engaging stakeholders can address them
- Describe effective communication channels for dissemination including effectively using new technology
- Identify two elements to include in your research design to assure you are “designing for dissemination”, in conjunction with your stakeholders
- Access and use key resources

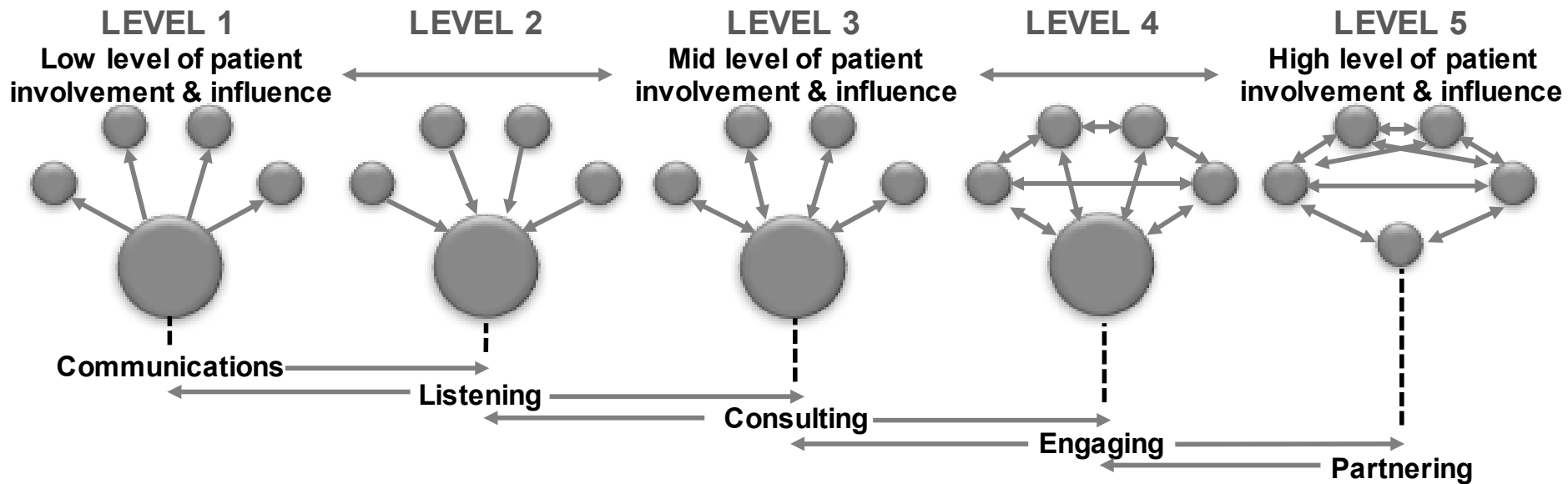


Agenda

- Context
 - Engagement framework to apply to dissemination
- 2 Case Studies
 - Continuous dissemination
 - Participants as disseminators
 - Social Media guidelines and analytics
- Hear from Patient Experience Ambassadors
- Application – selecting & mapping tools/approaches



Engagement Occurs Across a Continuum



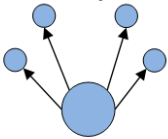
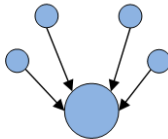
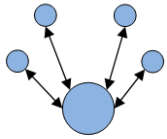
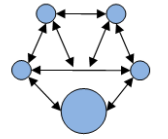
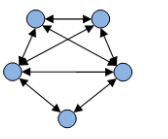
From: Health Canada. 2000. *Health Canada Policy Toolkit for Public Involvement in Decision Making*. Corporate Consultation Secretariat, Health Policy and Communications Branch, Health Canada, Retrieved May 29, 2013. < http://www.hc-sc.gc.ca/ahc-asc/pubs/_public-consult/2000decision/index-eng.php>.



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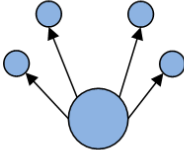
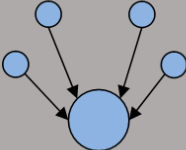
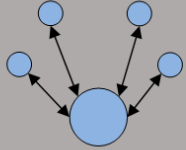
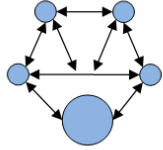
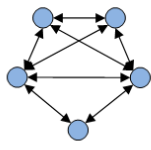
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High Touch and High Tech Options

Engagement Category		Inform/Educate	Gather	Discuss	Involve	Partner			
							Patients are recipients of info & education	Patients are informers	Patients & researchers discuss issues
Tools/Approaches	High Touch	<ul style="list-style-type: none"> • Visibility wall • Newsletter • Brochure • Posters (infographics) in clinics 	<ul style="list-style-type: none"> • Cycle time • Penless surveys • Suggestion boxes • In-person interview • Shadowing • Mystery shopping 	<ul style="list-style-type: none"> • Targeted meetings to clarify patient input • Focus group • 1:1 in-person discussion • Informal waiting room discussions 	<ul style="list-style-type: none"> • On-going patient feedback panels • Patients attend occasional research meetings • Town halls • Workshops • World Café 	<ul style="list-style-type: none"> • Patients join ongoing research meetings • Patients trained to: <ul style="list-style-type: none"> ○ code data ○ participate in dissemination (e.g. conferences, speakers bureau) 			
	High Tech	<ul style="list-style-type: none"> • Website/Apps/Blogs • Patient e-record/portal • Mass media (newspapers, TV, radio) • Email/ texts • Social Media • Live-streaming 	<ul style="list-style-type: none"> • Patient e-record/portal • Electronic surveys • Phone interview • Webinars with Q&A 	<ul style="list-style-type: none"> • Google hangouts • 1:1 phone discussion • Online discussion forum 	<ul style="list-style-type: none"> • Virtual town halls • Patient panels by video conferencing 	<ul style="list-style-type: none"> • Patients use Social Media for dissemination • Patients interviewed on news (TV or radio) 			



Engagement for Dissemination

Engagement Category		Inform/Educate	Gather	Discuss	Involve	Partner
		 <p>Patients are recipients of info & education</p>	 <p>Patients are informers</p>	 <p>Patients & researchers discuss issues</p>	 <p>Patients are advisors</p>	 <p>Patients are full participants in research</p>
Tools/Approaches	High Touch	<ul style="list-style-type: none"> • Visibility wall • Newsletter • Brochure • Posters (infographics) in clinics 	<ul style="list-style-type: none"> • Cycle time • Penless surveys • Suggestion boxes • In-person interview • Shadowing • Mystery shopping 	<ul style="list-style-type: none"> • Targeted meetings to clarify patient input • Focus group • 1:1 in-person discussion • Informal waiting room discussions 	<ul style="list-style-type: none"> • On-going patient feedback panels • Patients attend occasional research meetings • Town halls • Workshops • World Café 	<ul style="list-style-type: none"> • Patients join ongoing research meetings • Patients trained to: <ul style="list-style-type: none"> ○ code data ○ participate in dissemination (e.g. conferences, speakers bureau)
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Continuous Dissemination and Engagement

Continuous Dissemination throughout Project		High touch for dissemination	High tech for dissemination
	Recruitment		
	Project kick-off		
	Conduct of Research		
	Dissemination of Results		
	Celebrate Successes and Honor Stakeholders		

Adapted from: Lavalley, D. C., Wicks, P., Alfonso Cristancho, R., & Mullins, C. D. (2014). Stakeholder engagement in patient-centered outcomes research: high-touch or high-tech?. *Expert review of pharmacoeconomics & outcomes research*, 14(3), 335-344.



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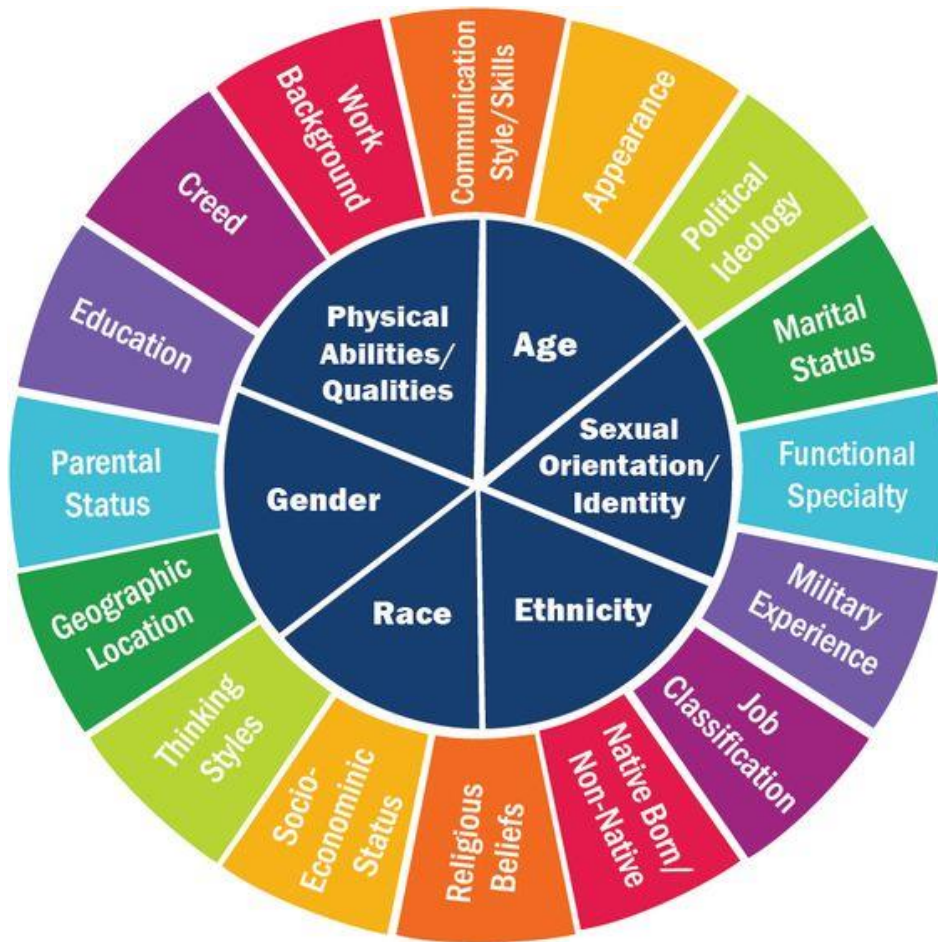
A Fundamental Engagement Challenge: Moving Beyond “The Usual Suspects”



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Diversity of Voices



Dimensions shape:

- Values
- Beliefs
- Experiences
- Expectations

Affect Health Outcomes

Technology as an Engagement Tool



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Example 1: The Dane 1 in 4 Project



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Branding



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Dane 1 In 4 Website & Social Media



The image shows a screenshot of the dane1in4.org website. The header features a logo with a stethoscope and a brain icon, and the text "dane1in4.org". A navigation menu includes "HOME", "ABOUT US", "BLOG", and "CONTACT". The main content area has the text "ADD your voice to the conversation" next to a photograph of a diverse group of people with their hands stacked in a circle. Below this is a "TELL YOUR STORY TO HELP OTHERS." section with a "CONTACT US" button.

dane1in4.org

HOME ABOUT US BLOG CONTACT

ADD
your voice
to the conversation

• ● •

TELL YOUR STORY TO HELP OTHERS.

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

CONTACT US >



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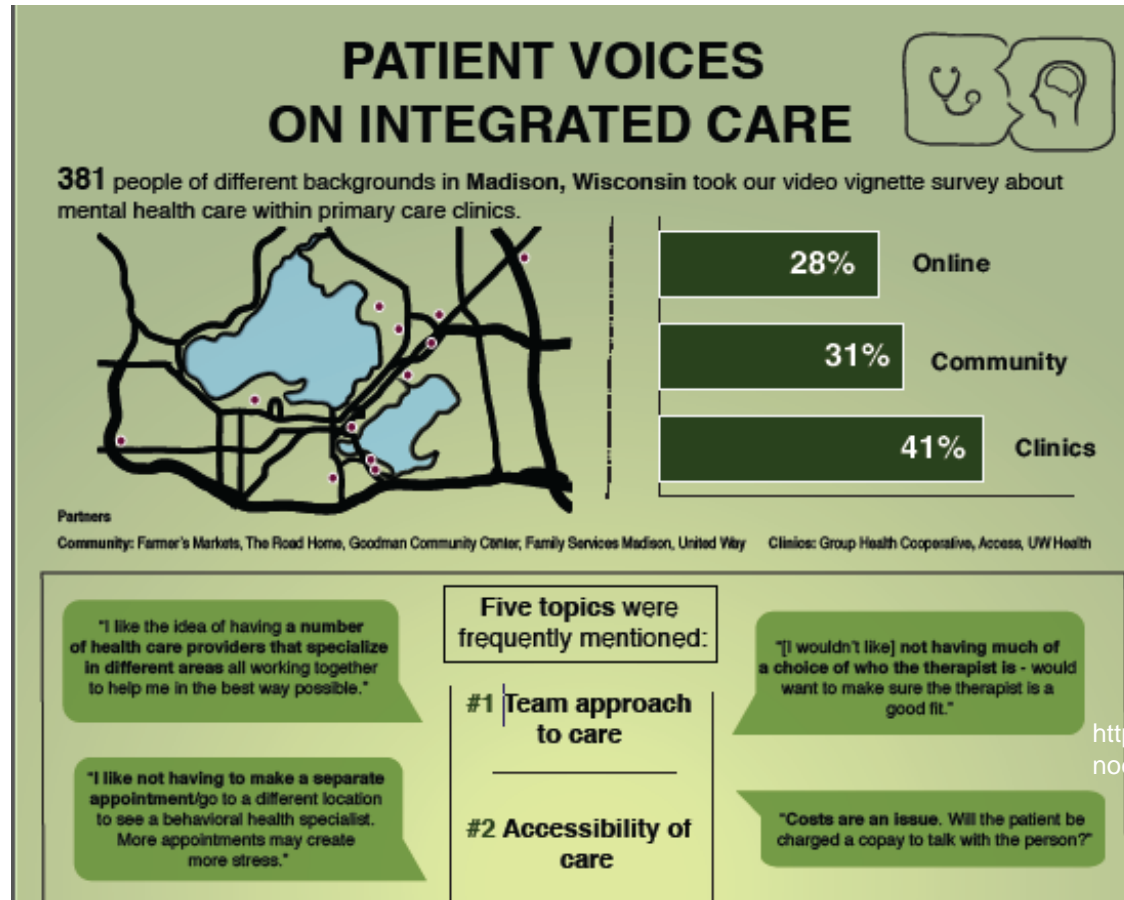
Stakeholder Partnering: United Way Forum



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Sharing Results Back



Example 2: Young Adults With Depression Module



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Health Experiences Research

- Interviewing people about their experiences with particular health conditions
- “...encourage the patient to tell the story of what has happened to them in their own way, focusing on the issues that are important to them.”

(Ziebland, Coulter et al., 2013)



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Health Experiences Research Network Steering Committee

Launched in in 2014

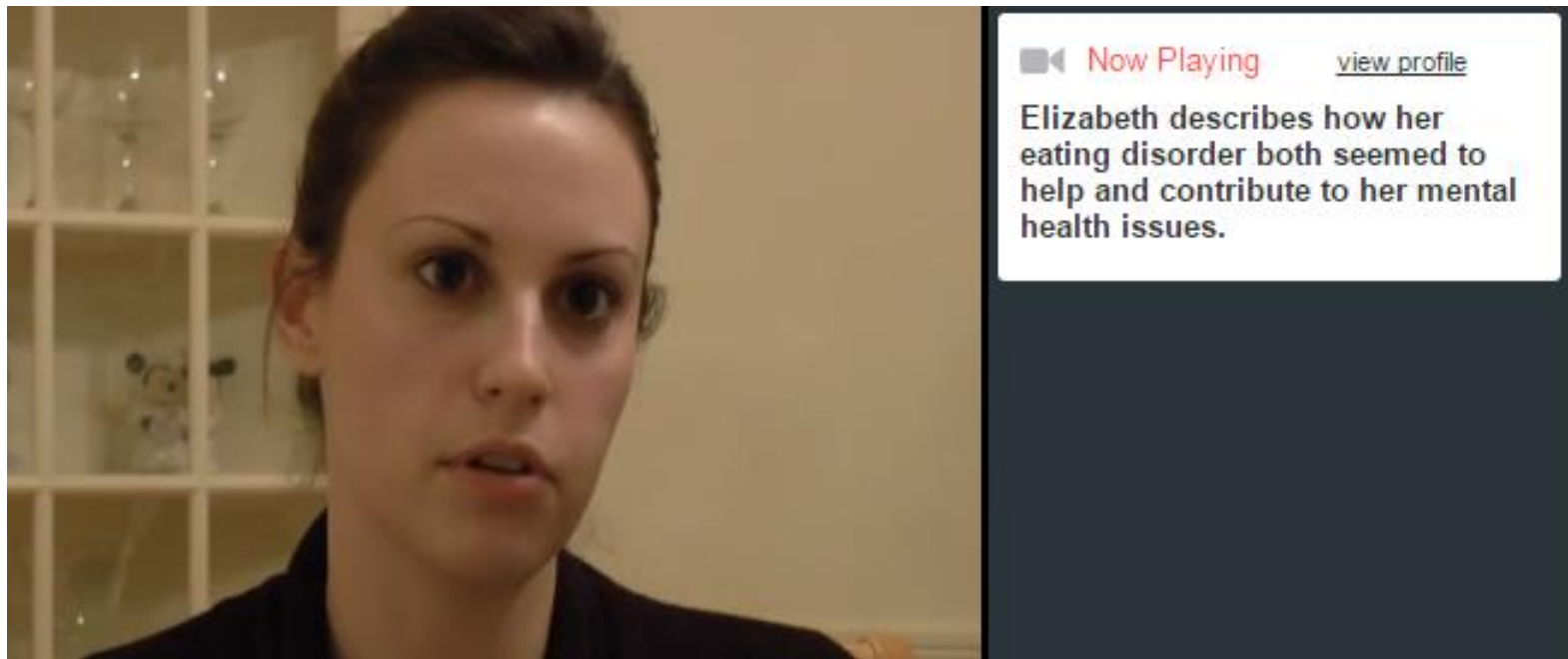
Rachel Grob, MA, PhD, Chair
Erika Cottrell, PhD, MPP
Kay Dickersin, PhD
Mark Helfand, MD, MPH
Kate Smith, PhD, MA
Nancy Pandhi, MD, PhD
Mark Schlesinger, PhD



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Interviews In Home Or Participant Preferred Setting



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



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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:** _____



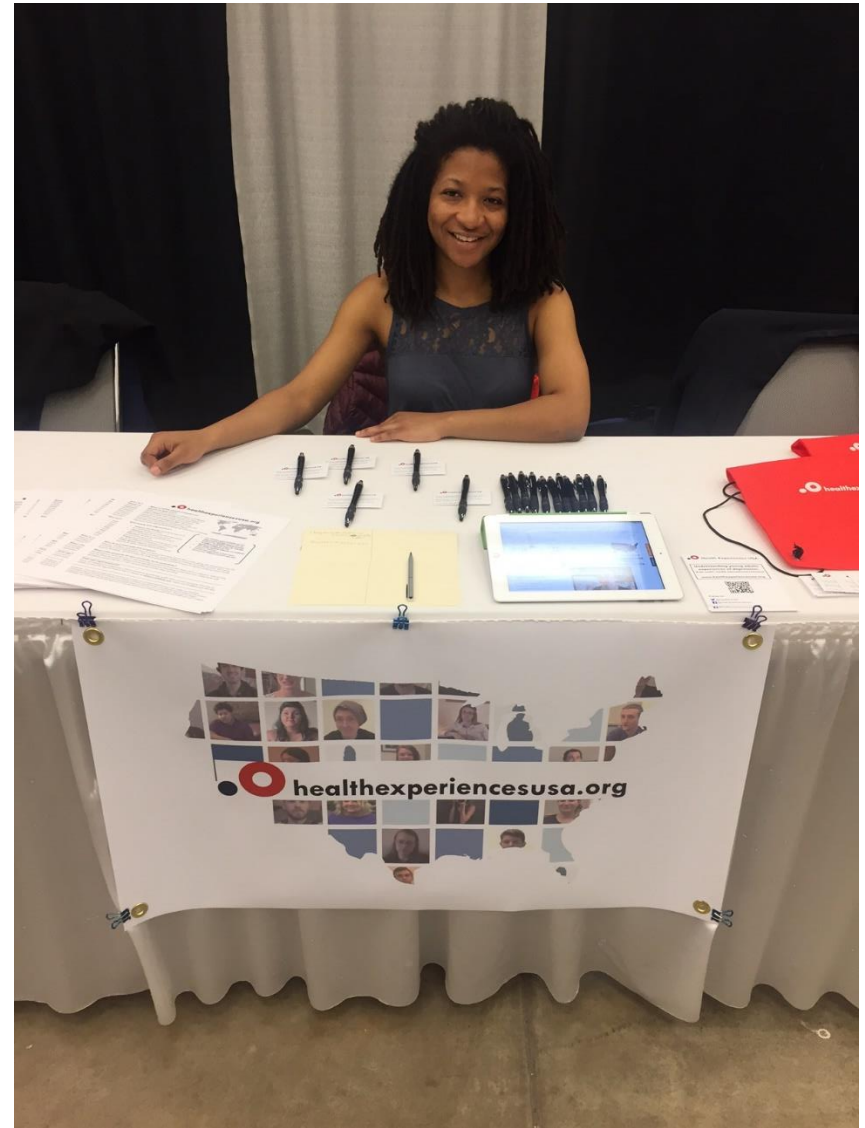
How Does HER Enhance Participant High Touch/High Tech Engagement?

- ✓ 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



Participants as Disseminators

- Identify Activities
- Training Program
- Logistics
(compensation, support to others)



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Dissemination Activities/Tactics

High Touch

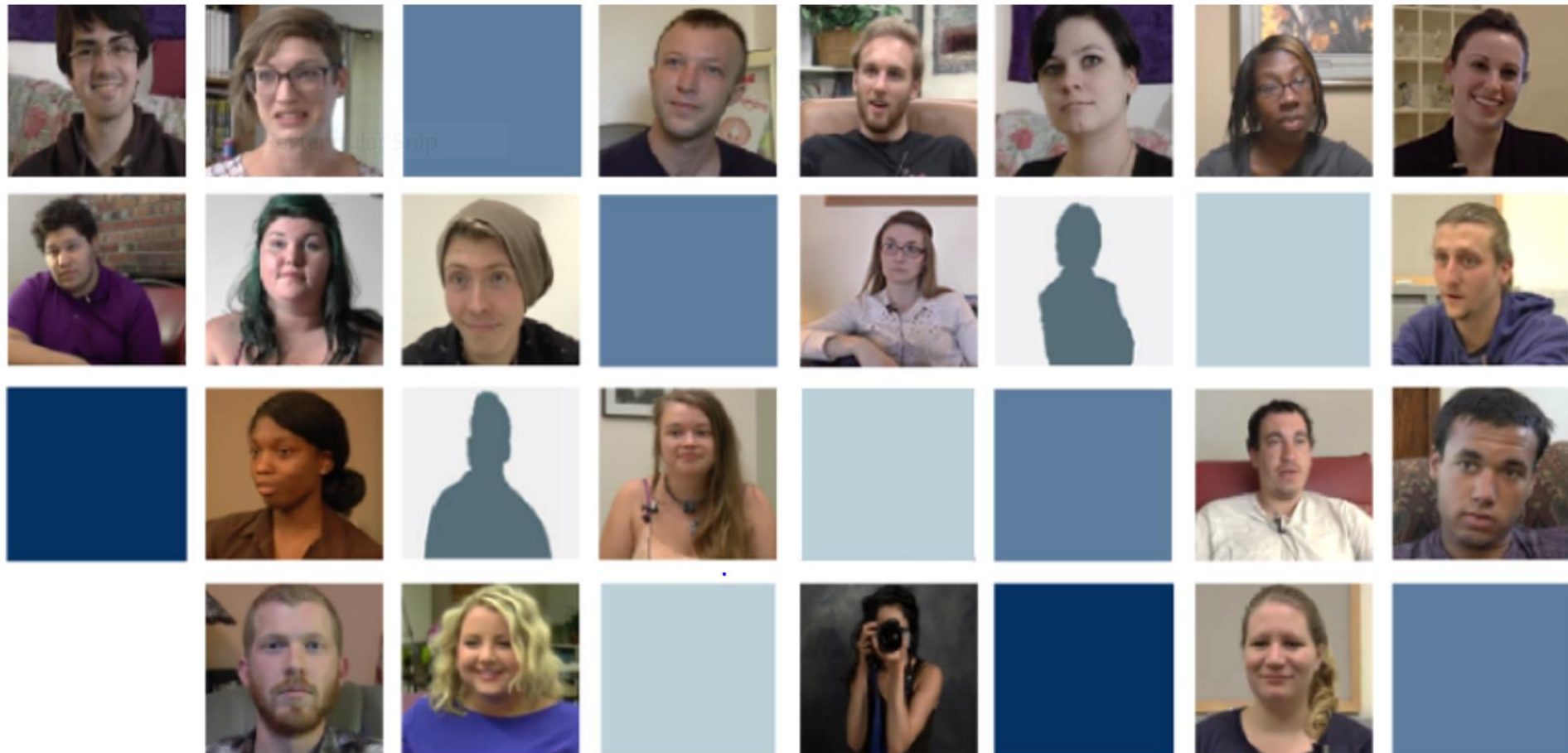
- Conferences
 - Tabling
 - Poster sessions
 - Presentations
- Speakers Bureau
 - Local community presentations

High Tech

- Social Media
 - Facebook
 - Twitter
 - Reddit
- TV News Interviews
- Letters to editors & Op Eds



Hear from our Ambassadors



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Training Components 1

- Ambassador Job Elements
- Teamwork
- Module’s Message
- Effective Messaging
- Telling Your Story
- Module Review
- Guidance Module
- Topic Facts & Stats
- Social Media
- Traditional Media
- Local Speakers Bureau



Training Components 2: Logistics

- Options to pay
- Conference Logistics
 - What to Wear
 - Financial details
 - Behavior & activities
- Guidance for Providing Resources, Support, or Emergency Help
- Who to contact



Training Components 3: Compensation

- Participate in training: **\$50**
- Conference base fee: **\$50/day**
- Conference exhibition: **\$50** (plus base fee)
- Social Media:
 - 15 posts, 5 engagements in 1 week: **\$50**
 - 5 posts, 2 engagements in 1 week: **\$20**
 - see the Social Media One-Sheet
- Blog Submission/Letter to the Editor/Op-Ed: **\$45**
 - If published: +\$15, total **\$60**
- Interviews with Media: **\$25**
- Organizing/Presenting at Speakers Bureau: **\$100-\$150**
 - Depending on whether or not other team members are involved in organizing the event.



Paying Ambassadors & Other Considerations

- Distinguished from "Participants" and "Engaged Stakeholders"/ "Advisors"
- Pre-travel honorariums
- Business Services
- Liability
- Academic Culture

See: "Paying Engaged Stakeholders" in "Compensation and Celebration of Deeply Engaged Stakeholders in

<https://www.hipxchange.org/DeeplyEngagingPatients>



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Twitter Guidelines

- Conversational
- Multimedia
- Pithy & Relevant
- Discoverable
- Consistent



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](https://www.nytimes.com)



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HealthExperiencesUSA Retweeted
National Council @nationalcouncil · May 19
Education is important! Here are some suicide warning signs that may help you recognize if a loved one is at risk. #MHM2017



20 22

HealthExperiencesUSA @HealthExUSA · May 17
We love this—self-care comes in many forms, and we don't have to do shopping, or getaways to recuperate.



2 1

HealthExperiencesUSA @HealthExUSA · May 17
Thank you so much @WISCTV_News3 for the wonderful piece on our resource! Find it here: healthexperiencesusa.org/depression/

WISCTV News 3 @WISCTV_News3
UW Health website speaks to young adults with depression #news3 channel3000.com/health/uw-heal...

HealthExperiencesUSA @HealthExUSA · May 22
If you're tired and mixed up this #mondaymorning, you're not alone and you don't have to be ashamed. #depression #mentalhealth

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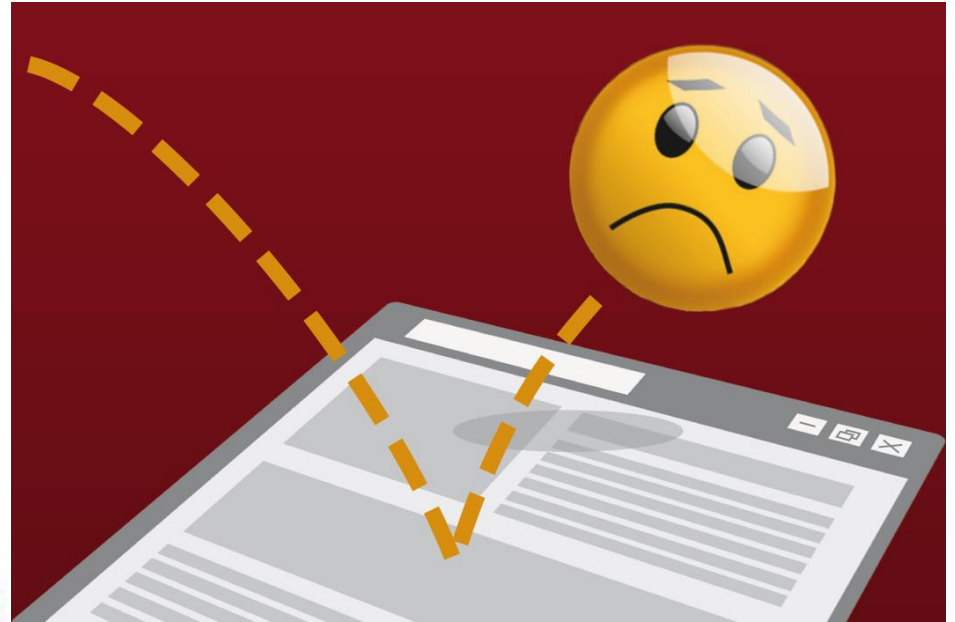
HealthExperiencesUSA @HealthExUSA · May 19
We are live with an AMA on the important Reddit community /r/depression. Check us out:



1

<https://twitter.com/HealthExUSA>

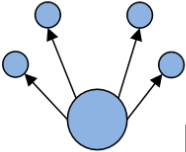
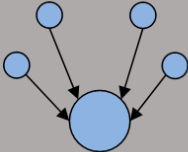
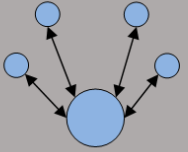
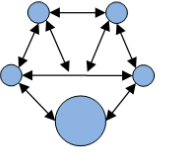
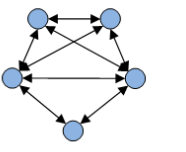
Analytics for ROI



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Selecting and Mapping Tools/Approaches

Engagement Category		Inform/Educate	Gather	Discuss	Involve	Partner
						
Engagement Category		Patients are recipients of info & education	Patients are informers	Patients & researchers discuss issues	Patients are advisors	Patients are full participants in research
Tools/Approaches	High Touch	<ul style="list-style-type: none"> • Visibility wall • Newsletter • Brochure • Posters (infographics) in clinics 	<ul style="list-style-type: none"> • Cycle time • Penless surveys • Suggestion boxes • In-person interview • Shadowing • Mystery shopping 	<ul style="list-style-type: none"> • Targeted meetings to clarify patient input • Focus group • 1:1 in-person discussion • Informal waiting room discussions 	<ul style="list-style-type: none"> • On-going patient feedback panels • Patients attend occasional research meetings • Town halls • Workshops • World Café 	<ul style="list-style-type: none"> • Patients join ongoing research meetings • Patients trained to: <ul style="list-style-type: none"> ○ code data ○ participate in dissemination (e.g. conferences, speakers bureau)
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Example tools: Visibility Wall



World Café



<http://www.theworldcafe.com/>



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Video Conferencing



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Tech Inclusion considerations

- How familiar is your 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?



Implementation Considerations

- Expertise
 - Knowledge of the tool
 - Experience with engagement
- Logistics
 - Timing
 - Costs & Compensation
 - Supplies
 - Location
- Diversity and inclusion
- Pros and cons of each tool
 - Mixing tools to address cons



Mapping for Continuous Dissemination

Continuous Dissemination throughout Project		High touch for dissemination	High tech for dissemination
	Recruitment		
	Project kick-off		
	Conduct of Research		
	Dissemination of Results		
	Celebrate Successes and Honor Stakeholders		

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Example from Dane 1 in 4

	High-touch for dissemination	High-tech for dissemination	
Continuous Dissemination throughout Project	Project kick-off	<ul style="list-style-type: none"> • Community forum at United Way • Mass Media – newspaper article, community radio 	<ul style="list-style-type: none"> • Website • Social Media: <ul style="list-style-type: none"> ○ Facebook • Twitter (<i>build presence</i>)
	Recruitment	<ul style="list-style-type: none"> • Through key community representatives 	<ul style="list-style-type: none"> • Website about research project • Branding project <ul style="list-style-type: none"> ○ Blog
	Conduct of Research	<ul style="list-style-type: none"> • At farmer’s market, community organizations, homeless shelters, clinic waiting rooms 	<ul style="list-style-type: none"> • Website • Social Media: <ul style="list-style-type: none"> ○ Facebook ○ Twitter (<i>about research and related activities</i>)
	Dissemination of Results	<ul style="list-style-type: none"> • Poster with Infographics distributed widely • Press Release • Traditional academic portals – conferences • Personal meetings with community representatives (loop back) 	<ul style="list-style-type: none"> • Partners posted on own websites • Website • Social Media: <ul style="list-style-type: none"> ○ Facebook ○ Twitter (<i>about results</i>) ○ Blog • Professional listservs • Email distribution
	Celebrate Successes and Honor Stakeholders	<ul style="list-style-type: none"> • Invite selective patients from focus group to join research team for next phase of research 	<ul style="list-style-type: none"> • Thank all community contributors and stakeholders via email

Q & A



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Publications and Resources

- 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.” *Joint Commission Journal on Quality and Patient Safety* 2014;40(12).
- Davis, S., Berkson, S., Gaines, M. Prajapati, P., Schwab, W., and Pandhi, N. Engaging Patients in Team-based Practice Redesign: Critical Reflections on Program Design. *Journal of General Internal Medicine*. *Journal of General Internal Medicine* 2015; in press.
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- Grande, D., Gollust, S. E., Pany, M., Seymour, J., Goss, A., Kilaru, A., & Meisel, Z. (2014). Translating research for health policy: researchers' perceptions and use of social media. Health Affairs, 10-1377.
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Acknowledgements

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- Thanks to Depression Module Co-PI Rachel Grob, Co-Is Meg Wise and Mark Schlesinger
- Dane 1&4, and the Young Adults with Depression Module were supported by the Clinical and Translational Science Award (CTSA) program, previously through the National Center for Research Resources (NCRR) grant 1UL1RR025011, and now by the National Center for Advancing Translational Sciences (NCATS), grant 9U54TR000021.
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