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

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Patient Experience Ambassadors
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

LEVEL 1
Low level of patient involvement & influence

LEVEL 2
Mid level of patient involvement & influence

LEVEL 3
Mid level of patient involvement & influence

LEVEL 4
High level of patient involvement & influence

LEVEL 5
High level of patient involvement & influence

Communications
Listening
Consulting
Engaging
Partnering

## High Touch and High Tech Options

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| Patients are recipients of info & education | • Visibility wall  
  • Newsletter  
  • Brochure  
  • Posters (infographics) in clinics | • Cycle time  
  • Penless surveys  
  • Suggestion boxes  
  • In-person interview  
  • Shadowing  
  • Mystery shopping | • Targeted meetings to clarify patient input  
  • Focus group  
  • 1:1 in-person discussion  
  • Informal waiting room discussions | • On-going patient feedback panels  
  • Patients attend occasional research meetings  
  • Town halls  
  • Workshops  
  • World Café | • Patients join ongoing research meetings  
  • Patients trained to:  
    - code data  
    - participate in dissemination (e.g. conferences, speakers bureau) |
| High Touch | • Website/Apps/Blogs  
  • Patient e-record/portal  
  • Mass media (newspapers, TV, radio)  
  • Email/texts  
  • Social Media  
  • Live-streaming | • Patient e-record/portal  
  • Electronic surveys  
  • Phone interview  
  • Webinars with Q&A | • Google hangouts  
  • 1:1 phone discussion  
  • Online discussion forum | • Virtual town halls  
  • Patient panels by video conferencing | • Patients use Social Media for dissemination  
  • Patients interviewed on news (TV or radio) |

**Community-Academic Partnerships**
UW Institute for Clinical and Translational Research
# Engagement for Dissemination

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Continuous Dissemination and Engagement

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

Dimensions shape:
- Values
- Beliefs
- Experiences
- Expectations

Affect Health Outcomes

http://web.jhu.edu/dlc/resources/diversity_wheel/index.html
Technology as an Engagement Tool
Example 1: The Dane 1 in 4 Project
Dane 1 In 4 Website & Social Media
Sharing Results Back

PATIENT VOICES ON INTEGRATED CARE

381 people of different backgrounds in Madison, Wisconsin took our video vignette survey about mental health care within primary care clinics.

- **Online**: 28%
- **Community**: 31%
- **Clinics**: 41%

**Five topics were frequently mentioned:**

1. **Team approach to care**
   - "I like the idea of having a number of health care providers that specialize in different areas all working together to help me in the best way possible."

2. **Accessibility of care**
   - "I like not having to make a separate appointment/go to a different location to see a behavioral health specialist. More appointments may create more stress."

3. **Fees**
   - "[I wouldn’t like] having much of a choice of who the therapist is - would want to make sure the therapist is a good fit."

4. **Communication**
   - "Costs are an issue. Will the patient be charged a copay to talk with the person?"

Community: Farmer’s Markets, The Road Home, Goodman Community Center, Family Services Madison, United Way

Clinics: Group Health Cooperative, Access, UW Health
Example 2: Young Adults With Depression Module
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)
Health Experiences Research Network
Steering Committee

Launched 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
Interviews In Home Or Participant Preferred Setting

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)
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
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
Twitter Guidelines

- Conversational
- Multimedia
- Pithy & Relevant
- Discoverable
- Consistent
Education is important! Here are some suicide warning signs that may help you recognize if a loved one is at risk. #MHM2017

Suicide Prevention @afspnational
May is MentalHealthAwareness month.

If you're tired and mixed up this #mondaymorning, you're not alone and you don't have to be ashamed. #depression #mentalhealth

We are live with an AMA on the important Reddit community /r/depression. Check us out:

Hey /r/depression, we're a group of researchers...
Hello /r/depression, We thank you for allowing us to share here, and we thank the mods for their permission. /r/depression is an important space,...

'Boring Self-Care' Drawings Celebrate Everyday Mental Health Wins
Let's talk about the radical act of taking care of yourself.
huffingtonpost.com

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

UW Health website speaks to young adults with depression #news3 channel3000.com/health/uw-heal...
Analytics for ROI

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## Selecting and Mapping Tools/Approaches

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<td>Patients &amp; researchers discuss issues</td>
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<td>Patients are full participants in research</td>
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### Tools/Approaches

#### High Touch
- Visiblity wall
- Newsletter
- Brochure
- Posters (infographics) in clinics
- Website/Apps/Blogs
- Patient e-records/portal
- Mass media (newspapers, TV, radio)
- Email/ texts
- Social Media
- Live-streaming

#### High Tech
- Cycle time
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Example tools: Visibility Wall

http://blog.hqc.sk.ca/2013/09/30/education-leaders-study-rqhrs-visibility-walls/
World Café

http://www.theworldcafe.com/

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Video Conferencing
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

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| **Project kick-off**                      | • Community forum at United Way  
• Mass Media – newspaper article, community radio | • Website  
• Social Media:  
  ○ Facebook  
  ○ Twitter (*build presence*) |
| **Recruitment**                           | • Through key community representatives | • Website about research project  
• Branding project  
  ○ Blog |
| **Conduct of Research**                   | • At farmer’s market, community organizations, homeless shelters, clinic waiting rooms | • Website  
• Social Media:  
  ○ Facebook  
  ○ Twitter (*about research and related activities*) |
| **Dissemination of Results**              | • Poster with Infographics distributed widely  
• Press Release  
• Traditional academic portals – conferences  
• Personal meetings with community representatives (loop back) | • Partners posted on own websites  
• Website  
• Social Media:  
  ○ Facebook  
  ○ Twitter (*about results*)  
  ○ Blog  
• Professional listservs  
• Email distribution |
| **Celebrate Successes and Honor Stakeholders** | • Invite selective patients from focus group to join research team for next phase of research | • Thank all community contributors and stakeholders via email |
Q & A
Publications and Resources


• https://www.hipxchange.org/StakeholderEngagementTools


Articles on Social Media

• Darling, E. S., Shiffman, D., Côté, I. M., & Drew, J. A. (2013). The role of Twitter in the life cycle of a scientific publication.
Acknowledgements

• These materials were created as part of a UW ICTR-CAP collaboration to create state-of-the-art resources to support patient and other stakeholder engagement in research. These activities are supported in part by grant UL1TR000427 to UW ICTR from NIH/NCATS, as well as the University of Wisconsin-Madison School of Medicine and Public Health’s Wisconsin Partnership Program, WPP-ICTR grant # 3086.

• This work would not have been possible without the participation of those involved in Dane 1in4, and the HERN Depression module.

• 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.

• Additional funding for the Depression Module was provided by the University of Wisconsin School of Medicine and Public Health, the Wisconsin Partnership Program, the University of Wisconsin Medical Foundation, the Center for Patient Partnerships, the University of Wisconsin Department of Family Medicine and Community Health, and the Health Innovation Program.
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