



Engaging Patient Advisors
To Improve Research Recruitment, Retention,
& Outcomes: Who, How, and Why?

June 6, 2018

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WHO? HOW? WHY? **Agenda**

1. Introductions
2. Discuss “*who, how & why*” of patient engagement
3. Reflect on session activities; share impressions and takeaways



**Wisconsin Network
for Research Support**

WINRS—Fast Facts

- ▶ 200+
- ▶ 100+
- ▶ 99%
- ▶ 20+
- ▶ 36 \$

WHO?

The CARDS®

(Community Advisors on Research Design and Strategies)

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WHO?

Stakeholders in Research

Concannon TW, Meissner P, Grunbaum JA, McElwee N, Guise JM, Santa J, Conway PH, Daudelin D, Morralo EH, Leslie LK. A new taxonomy for stakeholder engagement in patient centered outcomes research. *Journal of General Internal Medicine*. 2012 Aug; 27 (8):985-991. doi: 10.1007/s11606-012-2037-1

WHO?

Engagement Methods

- Interviews
- Focus groups
- Surveys, Delphi process
- Social media
- CARDS®, other existing groups
- Project-specific advisory boards
- One-time multi-stakeholder meeting
- Stakeholder employed on research team

HOW?

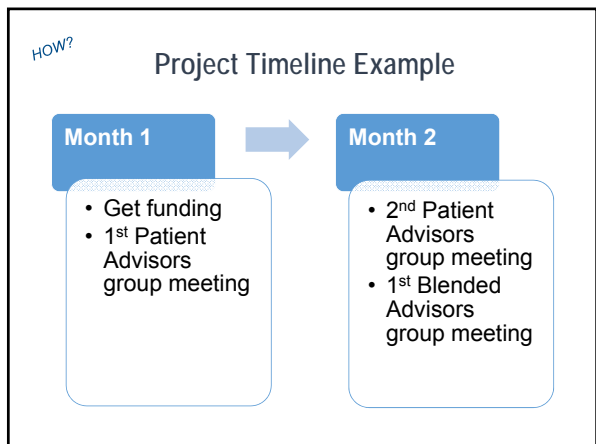
Tailoring Engagement Methods: Examples

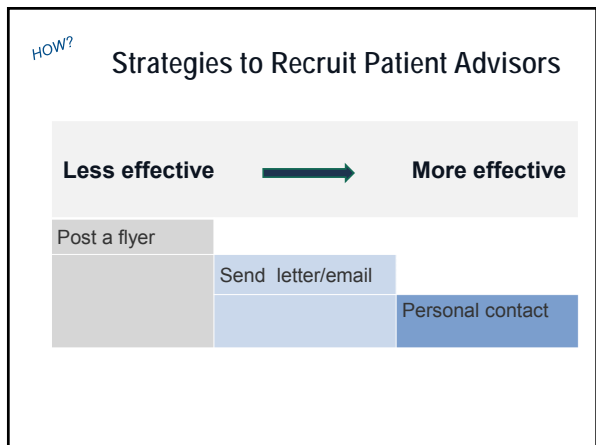
	Patients or Patient Advocacy Group	CARDS®	Patient Advisory Committee	Patient/Other Stakeholders on Team
Pre-funding	x			
Pilot	x	x	x	
Larger grant		x	x	x

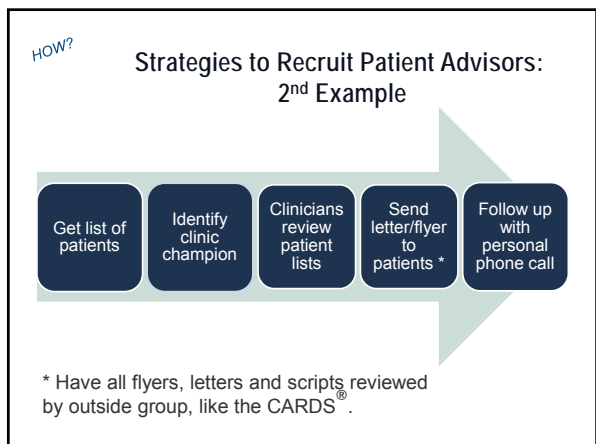
HOW?

We're off and running!
Ooops...









HOW?

Recruitment Flyer Template

- First impressions
 - What stands out to you?
 - What do you like?
 - Anything you don't like?
- Content
 - Clear?
 - Organized?
 - Sufficient?


HOW?

Best Practices for Recruiting Patient Advisors

Trusted partners who receive compensation	Outside perspective on methods and materials	Appropriate logistics and incentives
Respect, Sincerity, Reciprocity		

HOW?

Approaches to Preparing Patient Advisors



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HOW? **Examples:**
Orientation Objectives and Activities

Objectives	Activities
Establish group norms for respectful communication	PAs generate list of responses to "what helps you feel comfortable sharing your opinions in a group?" and discuss.
Distinguish helpful/not helpful feedback on research materials	PAs observe brief skit contrasting helpful/not helpful feedback and share their impressions.
Experience typical PA work	PAs offer feedback on real research materials.

WHY? **Comparing Before/After Materials**

- Overall readability
- Organization
- Tone
- Formatting
- Graphics

WHY? **Patient Advisor Impact: Study Names**

Original: Optimizing interventions to improve colorectal cancer screening - a qualitative approach
CARDS®: Improving colon cancer screening rates

Original: Detection and Neurological Impact of Cerebrovascular Events In Noncardiac Surgery Patients: A Cohort Evaluation (NeuroVISION)
CARDS®: Learning more about strokes during surgery

WHY? Patient Advisor Impact: Other Examples

- Flyer for recruiting study participants
- Process for recruiting study participants
- Consent Form
- Interview, survey, or focus group questions
 - “I am close with my roommate.”
 - “Many people feel more comfortable participating in research studies when they have relationships with the researchers or understand more about the work they are doing. What are your feelings about that?”
- Participant retention

HOW? Sustaining Engagement of Patient Advisors

- Create a welcoming space
- Let advisors know how their feedback is used by research team (“close the loop”)
- Acknowledge unique value of each individual
- Address concerns in timely, respectful way



HOW? Breakout:
Planning and Facilitating Meetings with Patient Advisors

- Basic principles
- Templates and tips
- Steps for planning meetings
- Questions and discussion

Engagement Resources

- Visit the WINRS website:
<https://wins.nursing.wisc.edu/>
- Click on the "Resources" tab to check out our
 - Toolkits (New one coming this fall!)
 - Journal articles
- Sign up for our newsletter, the WINRS Wire, at:
<http://bit.ly/2mSNDty>
- Follow us on Twitter: @UW_WINRS
- Contact us on our website or
grthomas@wisc.edu or blkaiser@wisc.edu

Acknowledgements

Funding

- UW-Madison School of Nursing
- UW-Madison Clinical and Translational Science Award (CTSA) program, through the NIH National Center for Advancing Translational Sciences (NCATS), grant UL1TR000427

Research materials

- Kara Hoppe, DO, UW Obstetrics & Gynecology
- Lisa Bratzke, PhD, RN, UW School of Nursing
- Andrea Gilmore-Bykovskiy, PhD, RN, UW School of Nursing

Questions and Comments?

Thank you!

*Please help us improve future workshops
by evaluating this session.*

<https://go.wisc.edu/m1x047>
