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

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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

The CARDS®
(Community Advisors on Research Design and Strategies)

Stakeholders in Research

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

Tailoring Engagement Methods: Examples

<table>
<thead>
<tr>
<th></th>
<th>Patients or Patient Advocacy Group</th>
<th>CARDS®</th>
<th>Patient Advisory Committee</th>
<th>Patient/Other Stakeholders on Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-funding</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Pilot</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
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<tr>
<td>Larger grant</td>
<td>x</td>
<td>x</td>
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We're off and running!
Ooops...
**Project Timeline Example**

**Month 1**
- Get funding
- 1st Patient Advisors group meeting

**Month 2**
- 2nd Patient Advisors group meeting
- 1st Blended Advisors group meeting

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**Strategies to Recruit Patient Advisors**

<table>
<thead>
<tr>
<th>Less effective</th>
<th>More effective</th>
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<tbody>
<tr>
<td>Post a flyer</td>
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<tr>
<td>Send letter/email</td>
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<tr>
<td>Personal contact</td>
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**Strategies to Recruit Patient Advisors: 2nd Example**

- Get list of patients
- Identify clinic champion
- Clinicians review patient lists
- Send letter/flyer to patients *
- Follow up with personal phone call

* Have all flyers, letters and scripts reviewed by outside group, like the CARDS®.
Recruitment Flyer Template

• First impressions
  – What stands out to you?
  – What do you like?
  – Anything you don’t like?

• Content
  – Clear?
  – Organized?
  – Sufficient?

Best Practices for Recruiting Patient Advisors

- Trusted partners who receive compensation
- Outside perspective on methods and materials
- Appropriate logistics and incentives

Respect, Sincerity, Reciprocity

Approaches to Preparing Patient Advisors

- Education
- Orientation
Examples: Orientation Objectives and Activities

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Activities</th>
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<tr>
<td>Establish group norms for respectful communication</td>
<td>PAs generate list of responses to &quot;what helps you feel comfortable sharing your opinions in a group?&quot; and discuss.</td>
</tr>
<tr>
<td>Distinguish helpful/not helpful feedback on research materials</td>
<td>PAs observe brief skit contrasting helpful/not helpful feedback and share their impressions.</td>
</tr>
<tr>
<td>Experience typical PA work</td>
<td>PAs offer feedback on real research materials.</td>
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Comparing Before/After Materials

- Overall readability
- Organization
- Tone
- Formatting
- Graphics

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
WHAT: 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://winrs.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

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Questions and Comments?
Thank you!

Please help us improve future workshops by evaluating this session.

https://go.wisc.edu/m1x047