How to Approach Recruiting and Retaining Patient Stakeholders: An Engagement Guide (HARPS)

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Patient & Community Stakeholder Engagement STRAIGHT AHEAD

What is HARPS?

How to Approach Recruiting and Retaining Patient Stakeholders: An Engagement Guide (HARPS) is a set of planning materials for health sciences researchers and others who want to engage patients and other stakeholders as advisors on projects, including patient-centered outcomes research (PCOR). HARPS contains a fillable "roadmap" for planning stakeholder engagement, video from a workshop demonstrating the roadmap, and supplemental videos.

- The roadmap is a fillable workbook that uses 10 guiding questions and supplemental Appendices to help develop ideas and plans for successful engagement of stakeholders.
- The 80-minute workshop video discusses the 10 guiding questions in the roadmap and addresses key considerations for patient stakeholder engagement.
- 22 supplemental videos (approximately 20-60 sec. each) feature patient stakeholders, community partners, and researchers discussing key topics related to engagement. Click the video icons - ▶ - to view these clips.

Who are patient stakeholders in research?

Patient stakeholders are people who use health care services or participate in health research. They can provide valuable advice across all stages of a research project, helping researchers identify possible recruitment barriers for study participants; develop targeted recruitment materials and strategies; design study procedures that minimize participant burden and help participants feel respected; recommend revisions to data collection instruments to improve readability and comprehension; interpret study findings; and plan dissemination of study results. All patients can provide useful input on research ideas and processes. However, it is important for researchers to intentionally seek advice from patients generally under-represented in the research enterprise. These patients include members of racial and ethnic minorities, people with incomes below the federal poverty threshold, children and adolescents, older adults, LGBTQ populations, and other groups that are sometimes marginalized or stigmatized.

How can HARPS be used?

Researchers and others can use HARPS both as an overview of best practices in stakeholder engagement and as a comprehensive resource for creating detailed engagement plans for patient stakeholders. Users who are new to patient-centered research and programs may find HARPS particularly useful as an overview of key considerations in patient stakeholder engagement. For users with experience creating engagement plans, HARPS can streamline and efficiently organize the process of developing a detailed engagement plan for grant applications. See more about HARPS on page 24.
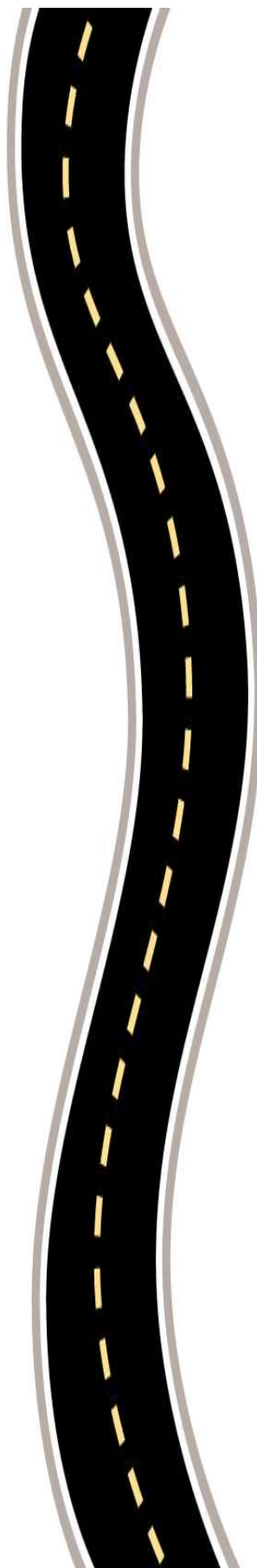
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1: Who Do I Want As Stakeholders?

This is a good place to start! Think about patients and other people who can offer unique and different viewpoints to you and your research team. This question sets the foundation for answering the other questions in this roadmap.

Decide what experiences/perspectives are most important for my research project

▶ ***Seeing study materials from a participant's perspective***

▶ ***Getting a fresh perspective on research***

- Particular type of stakeholder (patient, family member, caregiver, member of community, other)

- Particular demographic characteristics (age, gender, race, etc.)

  ▶ ***Engaging teen stakeholders to get unique insights***

- Particular geographic area

- Ability to speak English

- Ability to read

Other issues and questions to discuss with research team or consultants:

2: What Do I Want My Stakeholders to Do?

Patient stakeholders can offer helpful advice at every point of your research project, from developing research questions to revising study instruments to suggesting language for dissemination of study findings. This section can help you clarify what you want your stakeholders to do.

Decide what kind of feedback and advice I want from my stakeholders

- Review and provide feedback on written materials (recruitment flyers/letters, survey questions, etc.)

  ▶ ***Improving study materials with stakeholders***

  ▶ ***Developing patient-centered recruitment materials***

- Advise on study processes (communication with study participants, timing of study activities, etc.)

- Advise on "mid-course" project corrections (problems with recruitment/retention, other project problems)

- Advise on disseminating study results to lay audiences

- Give feedback on future research ideas or project plans

- Other:

Other issues and questions to discuss with research team or consultants:

3a: Where Will I Meet with Stakeholders?

Meeting locations and times that are convenient for researchers are often inconvenient for patient stakeholders, who may have limited transportation options or inflexible work schedules, and may not feel comfortable in academic or clinical settings. This section can help you be more successful recruiting and retaining patient stakeholders.

Possible site ▶ *Why a community location is important*

☐ Community center

☐ Library

☐ Church

☐ Other community setting

☐ Clinic

Site considerations

- Familiar and comfortable for stakeholders

- Accessible parking and public transit

- Travel time

- Access to childcare if needed

  ▶ *Removing barriers to participation in stakeholder advisory group*

- Seating area for spouses, partners, or caregivers

Information about room rental

- Reservation policies

- Rental fees and payment process

Other issues and questions to discuss with research team or consultants:

3b: When Will I Meet with Stakeholders?

Meeting frequency

☐ Once a month

☐ Every 2-4 months

☐ Every 6 months

☐ Other

Length of meetings

☐ 1 hour

☐ 90 minutes

☐ 2 hours

Suitable time of day for stakeholders (working adults, parents with young children, older adults, etc.)

☐ Morning

☐ Afternoon

☐ Evening

Other issues and questions to discuss with research team or consultants:

4: How Will I Recruit Patient Stakeholders?

Comprehensive recruitment plans describe who will recruit stakeholders, how they will recruit these people, and what recruitment materials they will use. One-on-one outreach is a key strategy for recruiting patient stakeholders. Identify community or clinic partners who are trusted by stakeholders and can assist you with recruitment. This section will help you develop a targeted recruitment plan for your patient stakeholders.

Decide how many stakeholders to recruit

- Desired number of stakeholders
- Recruitment goal (Recruit more stakeholders than you need, in case some withdraw)

Decide where to recruit

- Hospital or Clinic
- Community setting
- Residences

Decide who will recruit stakeholders

- Members of research team
- Partners (clinic champions, community organizations, advocacy or issue groups).

    ▶ *Working with a community partner to recruit members of a stakeholder advisory committee*

    See Appendix I: Contact Form for Researcher Outreach to Community and Clinic Partners, pp. 17-18

Select recruitment methods　▶ *Using community connections*

- Personal contact: face-to-face, phone calls
- Targeted mailings or emails
- Brochures or flyers posted in community or clinic settings
- Other

Create a name and acronym for your patient stakeholder group.

Examples: Stakeholder Advisory Committee (SAC); Patient Advisory Board (PAB); Patient Advisory Council (PAC).

Other issues and questions to discuss with research team or consultants:

5: How Will I Develop Effective Recruitment Materials?

Effective recruitment materials use straightforward, plain language to describe the work that stakeholders will do and what they can expect in return. Vet your materials with people from your stakeholder population or people who are very familiar with your stakeholder population. This section will help you design tailored recruitment materials that appeal to your prospective patient stakeholders.

Design appropriate recruitment materials for stakeholders

- Scripts for phone calls or in-person recruitment
- Flyer or brochure (See Appendix II: Stakeholder Advisory Committee Recruitment Flyer, p. 19.)
- Letter or email
- Video

Use plain language. Find tips and tools at:

- Plain Language at NIH
- Center for Plain Language

Describe benefits for stakeholders ▶️ *Paying stakeholders for their work*

- Payment:
- Chance to improve research and have positive impact

    ▶️ *Making a positive difference as a member of a stakeholder advisory committee*

    ▶️ *Describing your project to interest teenagers*

- Chance to meet new people and share opinions
- Food

Add other key information for stakeholders (e.g., where and when group will meet; see questions 1-3)

Get feedback on drafts of recruitment materials from members of stakeholder population

Other issues and questions to discuss with research team or consultants:

6. How Will I Prepare Stakeholders for Their Work?

A thoughtful orientation is particularly important for patient stakeholders. Orientation activities help build a sense of community and give people confidence that they know what to expect and that they have the skills to be effective in the stakeholder role. This section will help you develop a well-designed, interactive orientation that introduces your stakeholders to their work and provides them with practice giving feedback on real research materials.

WORKERS AHEAD

Review notes for Question 2 ("What Do I Want My Stakeholders To Do?")

Design 1-3 hour orientation to prepare stakeholders for their work

▶ *Completing an orientation boosts confidence of stakeholders*

• Download and review Patient Advisor Toolkit 1: Orientation for Patient Advisory Committee. PAT-1 is available for free download at: https://www.hipxchange.org/PAT-1. PAT-1 is a comprehensive set of resources for preparing patient advisors and research teams to work together. It includes topics such as:

1.) Discussing their role as advisors on the research project (See Appendix III: Membership Agreement for Stakeholder Advisory Committee, p. 20.)

2.) Recognizing common research terms and processes

3.) Communicating respectfully   ▶ *Orientation to practice skills*

4.) Contributing to effective teamwork

5.) Providing constructive feedback on research plans and materials

For additional assistance tailoring an orientation for your stakeholders, contact WINRS for a consultation

Other issues and questions to discuss with research team or consultants:

# 7. Who Will Lead Stakeholder Engagement For My Project?

Stakeholder engagement requires ongoing coordination by your research team. This section will help you identify staff to take responsibility for ongoing engagement activities and prepare a project budget that accurately reflects your personnel needs.

Task	Name of Person Who Will Handle Task
Prepare meeting agendas and materials	
Follow up with stakeholders (email reminders, RSVPs)	
Reserve meeting space	
Arrange child care and transportation	
Arrange for payments to stakeholders	
Purchase food, beverages, supplies	
Bring meeting supplies: flip chart and easel, markers, pens, meeting agendas	
Facilitate meetings with stakeholders	
Take meeting notes; write summary report of stakeholder recommendations	
Write lay meeting summary to send to stakeholders	
Meet with individual stakeholders to resolve any problems related to participation	

8: How Can I Facilitate Effective Meetings With Stakeholders?

Effective meetings with patient stakeholders produce meaningful input for the research team and reinforce the value of participation for your stakeholders. This section will help you simplify your preparation and help you plan and conduct effective stakeholder meetings.
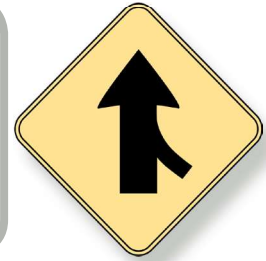
Use the same agenda outline for every meeting. Suggested agenda items:

- Opening question or "ice-breaker"

    ▶ ***Making stakeholder advisory committee meetings appealing to members***

- Examples of stakeholder input from previous meeting and how research team is using it (See Appendix IV: Sample Summary of Feedback from Stakeholder Advisory Committee, p. 21.)

    ▶ ***Giving feedback to stakeholders on how the research team used their advice***

- Brief update on project

- Action items: Materials for stakeholder review and feedback
    - Recruitment materials for study
    - Survey, interview, or focus group questions
    - Patient education or decision support materials
    - Reminder letters to study participants
    - Other items

Use a standard process for getting stakeholder feedback on study materials, issues, and other topics you bring to the group

- Explain the context:
    - Where will study participants view the materials?
    - Will participants view materials on their own, or will someone present and explain materials?

- Read materials aloud in small sections. After each section, ask questions.
    - "What is your initial impression?"
    - "Is it easy to understand?"
    - "Is there anything you don't like?"

- Facilitate discussion and record comments.

8: How Can I Facilitate Effective Meetings With Stakeholders?

Use of facilitators

- Use two: one facilitates discussion, one records feedback on flipchart
- Use same facilitators for all meetings with stakeholders to build trust and support open communication

    ▶️ ***Building trusting relationships between stakeholder advisors and research team***

    ▶️ ***Developing trust by using consistent facilitators***

Use a consistent group of stakeholders

   ▶️ ***Creating bonds within a consistent group***

- Encourage stakeholders to attend every meeting to promote group cohesion and effective teamwork
- Consider providing incentives that reward consistent attendance (e.g., bonus at end of project for attending all meetings)

Other issues and questions to discuss with research team or consultants:

9: How Can I Sustain the Involvement of My Stakeholders?

> *Patient stakeholders may face numerous barriers to participation over the course of your project. Making personal connections with stakeholders demonstrates that you care about them and reinforces their ties to the project. This section can help you strengthen stakeholder commitment to your project.*
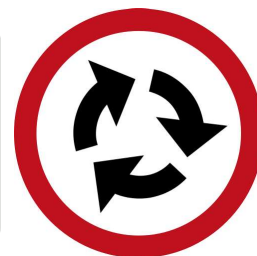
Acknowledge unique qualities and contributions of stakeholders

- Routinely give stakeholders specific examples of how their involvement improves research materials, processes, or outcomes

- Email or send personal thank-you notes ▶ *Thanking members with personal notes*

- Create a comfortable, welcoming space for stakeholders

  ▶ *Creating a welcoming space for stakeholders*

- Plan for a celebration at end of project or annually, depending on lifespan of project

Address problem issues in timely, respectful manner

- Regularly meet with research team to discuss what is working well in stakeholder meetings and what can be improved

- Meet as needed with individual stakeholders to acknowledge problems and develop solutions

Other issues and questions to discuss with research team or consultants:

10: How Do I Budget for Stakeholder Engagement?

Researchers often underestimate the cost of effective patient engagement. Stakeholder recruitment, orientation, and ongoing engagement all have budget implications. This section will help you prepare a detailed, realistic budget for patient engagement that you can use in grant applications.

Make sure your budget reflects appropriate funding for the following (see Appendix V: Budget Issues for Patient Engagment, pp 22-23)

- Staff time (research team, meeting facilitator)
- Community or clinic partner time
- Stakeholder engagement consultants
- Payment to stakeholders for meetings they attend
- Transportation (parking, bus passes, cab vouchers)
- Child care
- Refreshments at meetings
- Room rental for meetings
- Other compensation for community or clinic partner (see Appendix I, pp.17-18)

Other issues and questions to discuss with research team or consultants:
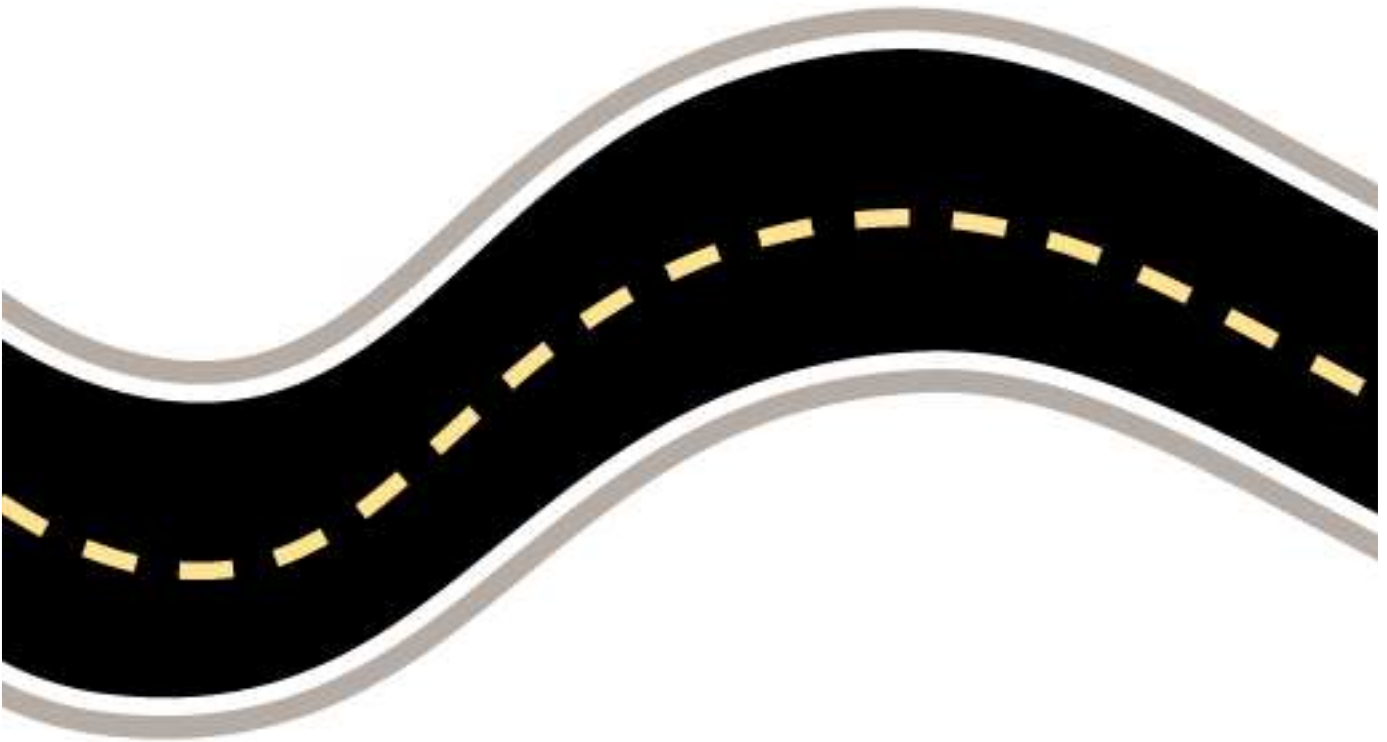
Appendices

▶ *Connecting with community organizations*

What is the name of your project? (Provide a title that most people would understand.)

Who should the community or clinic partner contact about this project?
Name:
Telephone Number:
Email:

What kind of help or support do you want from this community or clinic partner?

☐ Post recruitment materials at the partner's business location (attach sample)
☐ Speak with staff about recruitment strategies
☐ Provide space for project activities
☐ Write letter of support for grant application (attach draft)
☐ Other (please describe):

When do you want this help or support?

Who do you want involved in your project?
Age range:
Race/Ethnicity:
Other:

If your project involves patients or community members, what will you ask them to do? (3-4 key points)

Why might people want to participate in your project? (Stipend for participants, medical services, educational information, chance to help others, chance to socialize, etc.)

What can you offer to thank community or clinic partners?

☐ Pay for staff time on project

☐ Pay for use of meeting space

☐ Pay for educational materials, conference registrations, or training opportunities

☐ Donate goods or services

☐ Collaborate on grant-writing

☐ Other

How did you learn about this organization?

☐ Referred by (fill in name):

☐ Other (please describe):

What is your personal interest in your project? Why does it matter to you?

Want to help make (specific health issue) better?
Your advice is worth money!

We are looking for people to join our
Stakeholder Advisory Committee
to support (type of) research

Who are we looking for?
People in the (Madison area) who would like to share their ideas and opinions with University of Wisconsin-Madison researchers

Why do we need your help?
To help UW-Madison researchers understand how to make (insert study focus) research projects better

When do we meet?
(meeting time/date)

Where do we meet?
(location) We can help with transportation and childcare, if needed.

What does being on the committee involve?
- Complete a x-hour training
- Come to at least xx meetings during the year
- Get to meetings on time; stay for the whole meeting
- Listen and share your ideas

What will you get out of this?
- $xx for each meeting you attend
- Opportunity to give advice to researchers at UW-Madison
- Snacks at each meeting

Who should you call to get more information?
(contact info)

(insert captioned photo of contact person)

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APPENDIX III: Membership Agreement for Stakeholder Advisory Committee

<div align="center">

\<Project Name\>
Membership Agreement for Stakeholder Advisory Committee (SAC)

</div>

Thank you for your interest in being a member of the SAC! Here is a summary of our responsibilities to you and your responsibilities as a member of this group.

I understand that the project team will:
- Send me meeting announcements one week before the SAC meeting date
- Give me a chance to share my opinions and ideas at meetings
- Pay me \<$XX\> for each meeting I attend (must RSVP, be on time, stay for the entire meeting)
- Check in with me about how meetings are going for me

I understand my responsibilities related to SAC meetings. I will:
- Let \<staff name\> know as soon as possible if my contact information changes
- Let \<staff name\> know by \<date, time\> if I can come or not
- Arrive on time for meetings and stay for the whole meeting
- Provide feedback that is specific, relevant, and respectful
- Not discuss members' personal information or comments outside of the group or on social media
- Talk with \<staff name\> if I have concerns about the SAC or my participation

Project Team Contact Information
\<name\>
\<telephone number\>
\<email\>

APPENDIX IV: Sample Summary of Feedback from Stakeholder Advisory Committee

Meeting Topic: Encourage completion of surveys	SAC Feedback	Revised Research Processes
Project staff needed to send two emails to parent: one with parent survey and one with teen survey. Subject lines for parent and teen emails looked similar	*Similar subject lines could lead parents to overlook or discard one of the messages. Recommend using separate subject lines for parents and teens.*	Final emails had distinctive subject lines for PARENTS and TEENS.
Original email mentioned "gift card."	*Teens may be more likely to complete survey if they have a choice of cards. Recommend offering cards with broad appeal for both teens and parents.*	Final email explained that people who complete the survey can choose from two cards (Target, Amazon).
Email had confusing language about whether participants had to complete the survey all at once.	*People may decide not to do survey if they think they need to finish all at once or have to start over if they stop in the middle of the survey. Recommend inserting specific language about saving and restarting survey.*	Final email explained that participants can stop at any point, save the survey, and restart the survey later wherever they stopped.

APPENDIX V: Budget Issues for Stakeholder Engagement

CATEGORY	GOAL	COST	QUESTIONS
Recruiting Advisors	Identify and connect with potential stakeholder advisors		
Project staff time			Who will develop recruitment materials? Who will review these materials? Who will make final decisions on content and format?
Community Center staff time			Do I need to connect with people outside the UW to reach my target stakeholders? Who? Will I build on existing relationship or initiate a new relationship?
Clinic staff time			Will I have clinic staff recruit stakeholders for me?
Recruitment material costs (mailings, web site, DVDs, printing, etc.)			What materials and methods will be most effective to reach my target stakeholders?
Training/Orientation	Help stakeholders understand role and prepare them for success		
Staff time to: manage training logistics, develop tailored training, deliver and evaluate training			Who will develop training or adapt existing training? Who will print, collate training materials for facilitators, stakeholders? Who will schedule training, reserve space, arrange for food?
Room rental			Where will the training/ orientation be held?
Communtiy liason time			Do I need help/support from staff outside the UW?
Food			How long is the training? What time of day? What kind of refreshments are appropriate?
Transportation			Will stakeholders need help with transportation? Does location have easy parking? Do I need to cover cost of parking? Is training site easily accessible by public transportation?

APPENDIX 5: Budget Issues for Stakeholder Engagement

CATEGORY	GOAL	COST	QUESTIONS
Childcare			Will stakeholders need help with childcare? Can someone provide on-site care?
Equipment, supplies			Will I have printing costs for training materials? Will I need flip charts or a white board? Will I need other supplies (pens, markers for flip chart, note cards, name tags)?
Ongoing Meetings	Run meetings that produce meaningful results for all involved		
Staff time to: manage project logistics, plan and facilitate stakeholder meetings, maintain communication with stakeholders, trouble-shoot issues			Who will handle meeting logistics? Who will be develop meeting agendas and appropriate activities? Who will maintain communciation with stakeholders? Who will facilitate meetings?
Room rental and equipment			See questions above
Community/clinic liason time (Think creatively about what you can give back to partner organizations. See Appendix I, pp. 17-18.)			Do I want outside help with ongoing group support - managing RSVPs, setting up childcare/transportation, etc.?
Food			See questions above
Transportation			See questions above
Childcare			See questions above
Technology			Will I use phone/video conferencing for meetings?

HARPS is based on work originally conducted by the Wisconsin Network for Research Support (WINRS), from 2010 - 2013 with funding from a National Institute of Nursing Research grant (Principal Investigator: Barbara Bowers, PhD, RN). For one of the grant aims, WINRS developed two community advisory boards comprised of diverse community members; these ongoing boards are the Community Advisors on Research Design and Strategies (CARDS)®.1, 2 The content in HARPS is grounded in processes and tools that WINRS created for recruiting, training, facilitating, and sustaining the CARDS®. From 2014 - 2016, WINRS provided consultation services to Dr. Elizabeth Cox, MD, PhD on patient engagement for her PCORI-funded study "Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources". Together, WINRS and Dr. Cox adapted processes and tools used successfully with the CARDS® for the parent, teen, and youth advisory boards in her project. The planning tools in HARPS reflect the practice-based knowledge of the developers on engaging patient stakeholders.

1. Kaiser, B. L., Thomas, G. R., & Bowers, B. J. (in press). A case study of engaging hard-to-reach participants in the research process: Community Advisors on Research Design and Strategies (CARDS)®. NIHMSID 819210 (PMCID in process.)
2. Bowers, B. J., Krupp, A., & Jacobson, N. (in press). Can lay community advisors improve recruitment of underrepresented populations?
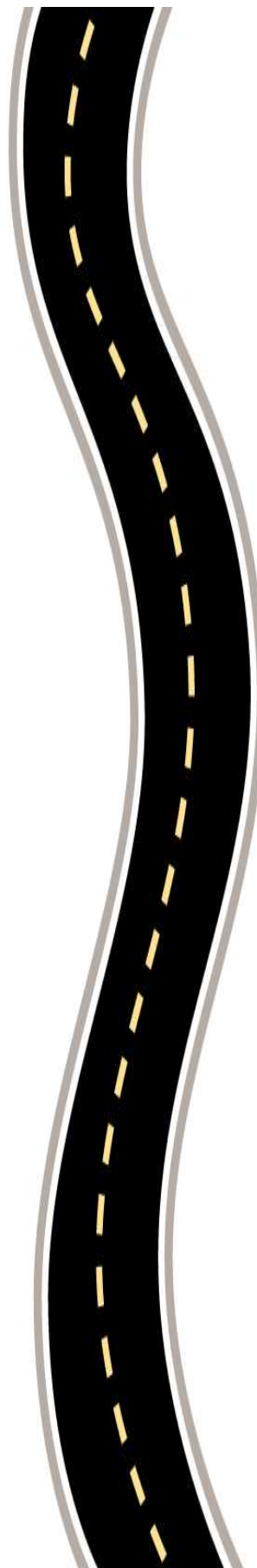
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Betty Kaiser, PhD, RN is Director of Community Training for WINRS. Dr. Kaiser specializes in developing orientation programs for patient and community partners who work with researchers. She works with WINRS co-Director Gay Thomas to adapt the CARDS® training for other research teams and support the effective use of patient stakeholder groups.

Gay Thomas, MA is Director of Community Engagement for WINRS. The focus of her work is to help health sciences researchers improve their project plans and materials through constructive engagement with patients and community members. She led the development of the CARDS® program and has been the primary liaison between researchers and the CARDS®. Ms. Thomas and Dr. Kaiser consult with researchers on effective patient engagement at many levels, including effective meeting practices and strategies to sustain patient stakeholder participation in research projects.

Elizabeth Cox, MD, PhD is an Associate Professor and Director of the Program of Research on Outcomes for Kids (PROKids) at the University of Wisconsin – Madison Department of Pediatrics. Her research improves health outcomes

by redesigning healthcare to meet the needs of patients as well as other stakeholders such as providers, payors, and policymakers. Her work uses accepted implementation techniques and validated measures of patient-reported outcomes to provide rigorous comparisons of the effectiveness of patient-centered interventions in clinical practice.

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Companion Resource

PAT-1 (https://www.hipxchange.org/PAT-1) is a comprehensive set of modifiable resources for conducting an orientation with patient advisors. The toolkit provides a complete, step-by-step guide to preparing patient advisors to work effectively with researchers. Researchers can use HARPS to develop an overall plan for patient stakeholder engagement and then adapt the materials in PAT-1 to create a tailored orientation program for patient stakeholders..

Funding

Re-using HARPS

HARPS exists for the benefit of the health care community. These materials are available free of charge and can be used without permission; however, we ask that you register with HIPxChange prior to using HARPS so that we may provide information on usage to our funders. It is acceptable to link to this website without express permission. If you decide to use these materials, we ask that you please credit the Wisconsin Network for Research Support (WINRS), the University of Wisconsin – Madison School of Nursing, the University of Wisconsin – Madison Department of Pediatrics, and the UW Health Innovation Program. Users of the toolkit can contact WINRS for help using and adapting the materials: https://winrs.nursing.wisc.edu/

The Wisconsin Network for Research Support
Innovative patient and community engagement services for researchers

kids
Program of Research on Outcomes for Kids
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