



WISCONSIN NETWORK FOR RESEARCH SUPPORT (WINRS)

STAKEHOLDER ENGAGEMENT IN TRANSLATIONAL RESEARCH

PATIENTS, COMMUNITIES AND ORGANIZATIONS

WHO WE ARE

[Wisconsin Network for Research Support](#) (WINRS) is a resource for patient and community engagement and research equity. WINRS provides a suite of consultation services to support researchers in effectively recruiting diverse study participants and engaging stakeholders to advise on projects, especially people from underrepresented and under-served communities.

WINRS staff also coordinate meetings with [CARDS](#)[®] (Community Advisors on Research Design and Strategies), two standing focus groups of Madison community members affiliated with Goodman Community Center and Lussier Community Education Center. CARDS[®] draw on their lived experiences to offer researchers actionable feedback on a wide range of project plans and materials, including recruitment strategies and materials, consent forms, survey and interview questions, program handouts, smartphone apps, websites, and more. The CARDS[®] bring valuable perspectives from diverse racial, ethnic, socioeconomic and educational backgrounds.

WINRS Staff: Kat Phelps, PhD; Mariana Garcia, PhD. WINRS Faculty Advisor: Barb King, PhD, APRN-BC, FAAN

WHAT WE OFFER: SERVICES

For researchers without funding: WINRS provides an initial consultation at no cost.

- Determine if there is a fit between researcher needs and WINRS services
- Share strategies for recruiting, working with, and retaining diverse study participants and stakeholders
- Offer advice on budgeting for successful patient/community engagement
- Suggest additional resources or strategies that might benefit the researcher's program of research

WINRS will also provide limited ongoing consultation directly related to grant development.

- Prepare detailed scope of work document and budget for WINRS consultation services
- Provide letter of support
- Review and offer recommendations on grant sections related to study participant/ stakeholder recruitment and ongoing engagement.

For researchers with funding: WINRS offers a variety of services which are available across the full life cycle of research projects, both to researchers at the UW-Madison and across the country. WINRS services are relevant to all research involving patients/the public.

- Advise on strategies for successful recruitment and retention of stakeholders or research participants, particularly (not exclusively) strategies for underrepresented populations
- Develop and deliver tailored orientation programs to prepare patient/community stakeholders for effective participation on advisory boards:
 - Programs for short or long-term stakeholder roles
 - Orientations tailored to prepare stakeholders for engagement in either patient/community advisory boards or in multi-stakeholder meetings

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- “Train the trainer” programs to prepare research staff to deliver stakeholder orientation sessions
- Provide ongoing coaching and templates to research teams to sustain productive advisory groups, including:
 - Effective agenda-setting, meeting facilitation, trouble-shooting ineffective meetings
 - Models for useful meeting summaries for both stakeholders and the research team
 - Strategies and practices to sustain stakeholder participation over time
- Use plain language principles to revise research materials for patients/stakeholders/public, including:
 - Recruitment materials
 - Data collection instruments (survey or interview questions)
 - Focus group scripts and activities
 - Community abstracts for non-scientist reviewers
- Coordinate Community Advisors on Research Design and Strategies (CARDS)[®] meetings
 - Plan and facilitate 90-minute meeting with group of diverse community members who review and provide feedback on research plans and any patient/public-facing research materials
 - Provide detailed meeting summary and revised documents based on CARDS[®] feedback

ABOUT PAYMENT

Fee-for-service model, contact WINRS for details; Fee waived for pre-funding consultation.

ABOUT THE INTAKE PROCESS

An initial exchange (e-mail or phone conversation) will help to determine general “fit” between researcher needs and WINRS services. The WINRS team will review any draft materials the research team shares, and schedule a longer follow-up meeting (in person or virtually) to discuss specific options.

STATEMENT: ARE WE A GOOD FIT FOR YOUR NEEDS?

Any researchers wanting to involve patients or community members in their research, either as research study participants or as stakeholder advisors, can benefit from WINRS resources. This includes researchers conducting clinical trials.

CONTACT INFORMATION

For more information, please contact Kat Phelps; kephelps@wisc.edu



UW ICTR-CAP Partner Programs Supporting Stakeholder Engagement in Translational Research

*[Center for Patient Partnerships](#) * [Program of Research on Outcomes for Kids](#) *
* [Sonderegger Research Center](#) * [Wisconsin Network for Research Support](#) *

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