**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 patient and community engagement resource. WINRS provides a suite of consultation services that address a persistent problem for researchers – how to effectively engage participants, especially people from under-represented communities or “hard to reach” populations. Services include: development of tailored training programs for community or patient stakeholders; best practices to sustain lay stakeholder engagement; review of consumer-facing materials; and advice on strategies for successful recruitment and retention of study/program participants. WINRS staff also coordinate meetings with *CARDs* (Community Advisors on Research Design and Strategies)®, focus groups of Madison community members from diverse racial, socioeconomic, and educational backgrounds who are trained to give feedback to investigators on recruitment plans and materials, consent forms, survey or interview questions, smartphone apps, websites and more. WINRS services are relevant for any researchers who want to engage people as research participants or study stakeholders. **Staff:** Betty Kaiser, PhD, RN; Gay Thomas, MA; Kaitlin Svabeck, MA. **Faculty Advisor:** Barb Bowers, RN, PhD, UW-Madison School of Nursing.

**What We Offer: Services**

**For researchers without funding:** WINRS provides an initial consultation at no cost. This consultation is intended to ...

- Determine if there is a fit between researcher needs and WINRS services
- Share strategies for recruiting, working with, and retaining diverse population of 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, including ...

- Prepare detailed scope of work document and budget for WINRS consultation services
- Provide letter of support
- Review and provide recommendation 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 their research partners at other sites. 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 training programs to prepare patient/public stakeholders for effective participation on stakeholder 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
- “Train the trainer” programs to prepare research staff to deliver stakeholder trainings

Provide ongoing coaching and templates to research teams to sustain productive stakeholder 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 life of desired engagement

Revise research materials for patients/stakeholders/public using plain language principles, including:
- Recruitment materials
- Data collection instruments (survey or interview questions)
- Focus group scripts and activities
- Community abstracts for non-scientist reviewers

Community Advisors on Research Design and Strategies (CARDS)*
- Plan and facilitate 90-minute meeting with group of lay community members who review and provide feedback 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 brief pre-funding consultation.

**CONTACT INFORMATION:** For more information, please contact Gay Thomas, MA; grthomas@wisc.edu, or Betty Kaiser, RN, PhD; blkaiser@wisc.edu

**ABOUT THE INTAKE PROCESS**
An initial phone conversation determines general “fit” between researcher needs and WINRS services. The WINRS team may review any draft materials the research team can share, followed by a longer follow-up meeting (in person or by phone) to discuss specific options

**STATEMENT: ARE WE A GOOD FIT FOR YOUR NEEDS?**
Any researchers wanting to involve non-providers, 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. WINRS can provide services to researchers doing Community Based Participatory Research (CPBR), but our primary focus is on other researchers interested in patient/public engagement.

**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
* VA Hospital Research Program  * Wisconsin Network for Research Support  * Wisconsin Surgical Outcomes Research Program*

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