Collaborating for the Advancement of Interdisciplinary Research in Benign

Stakeholder Engagement Basics for Health Science Researchers: Putting the Pieces Together



SESSION 2

RESEARCH IN NURSING & HEALTH

A Case Study of Engaging Hard-to-Reach Participants in the Research Process: Community Advisors on Research Design and Strategies (CARDS)®

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Abstract: Lack of diversity among study participants in clinical research limits progress in eliminating health disparities. The engagement of lay stakeholders, such as patient or community advisory boards (CABs), has the potential to increase recruitment and retention of underrepresented groups by providing a structure for gathering feedback on research plans and materials from this target population. However, many CABs intentionally recruit prominent stakeholders who are connected to or comfortable with research and academia and thus may not accurately represent the perspectives of underrepresented groups who have been labeled hard-to-reach, including racial minorities and low-income or low-literacy populations. We developed a partnership between the University of Wisconsin-Madison School of Nursing and two community centers to deliberately engage hard-to-reach people in two lay advisory groups, the Community Advisors on Research Design and Strategies (CARDS)®. Community center staff recruited the CARDS from center programs, including parenting and childcare programs, women's support groups, food pantries, and senior meal programs. The CARDS model differs from other CABs in its participants, processes, and outcomes. Since 2010, the CARDS have met monthly with nurses and other researchers, helping them understand how research processes and the language, tone, appearance, and organization of research materials can discourage people from enrolling in clinical studies. We have successfully used the CARDS model to bring hard-to-reach populations into the research process and have sustained their participation. The model represents a promising strategy for increasing the diversity of participants in clinical research. © 2016 Wiley Periodicals, Inc.

Keywords: subject recruitment; healthcare disparities; vulnerable populations; advisory committees; stakeholder engagement

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The elimination of health disparities is a national priority (National Institute on Minority Health and Health Disparities, 2016; US Department of Health and Human Services, 2016). Clinical researchers can play an important role in eliminating health disparities by making novel treatments available to underserved populations and identifying the effectiveness of particular treatments for particular populations. However, progress toward eliminating health disparities has been hindered by lack of participant diversity in clinical research studies (Kitterman, Cheng, Dilts, & Orwoll, 2011; Schroen et al., 2010). Researchers often do not reach recruitment goals for hard-to-reach participants such as racial and ethnic minorities and people with low income. Reasons for low recruitment include mistrust of research, perceived risks, and lack of culturally appropriate information about opportunities to participate in research (Ford et al., 2008), as well as burdens such as time commitment and lengthy questionnaires (Paskett et al., 2008).

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A recommended strategy for overcoming barriers to recruitment is patient and community stakeholder involvement in the design and conduct of clinical trials (Institute of Medicine, 2011). One popular form of stakeholder involvement is community advisory boards (CABs). CABs serve several functions, depending on the project mission and requirements. They provide input into research agendas; serve as gatekeepers for researcher entry into communities; formally approve projects; and influence the design, conduct, and implementation of studies (Fernandez-Pena et al., 2008; Silvestre, Quinn, & Rinaldo, 2010; Strauss et al., 2001).

Recommendations for CAB membership often emphasize inclusion of influential stakeholders and opinion leaders from the community (D'Alonzo, 2010). Typical CAB members include service providers, community leaders, and representatives of local agencies and organizations (Newman et al., 2011); in this paper, high-level stakeholders are referred to as "prominent community representatives." Prominent community representatives bring valuable skills, perspectives, and resources to CABs due to their experience with group and meeting processes, influence and connections within the community, and decision-making power within their organizations.

CABs also sometimes include lay stakeholders who are not prominent community representatives but can bring an important viewpoint to a research project, such as residents of a particular neighborhood or patients or caregivers with experience related to a particular health issue (James et al., 2011; Pinto, Spector, Rahman, & Gastolomendo, 2013). Lay stakeholders can help researchers improve the cultural sensitivity and appropriateness of recruitment materials and methods; recommend study implementation strategies (Joosten et al., 2015); and design relevant, meaningful interventions (GreenMills, Davison, Gordon, Kaigang, & Jurkowski, 2013). The perspectives of lay stakeholders who are disconnected from academia and local power structures may offer clinical researchers unique insights and perspectives on recruitment barriers and strategies for improving recruitment and retention of hard-to-reach populations. In this paper, we (the authors) describe the origins, participants, processes, and outcomes of a unique CAB comprised solely of lay stakeholders that brings voices of rarely heard groups into the research enterprise.

Project Origins and Community—Academic Partnership

Our team at the University of Wisconsin-Madison (UW-Madison) School of Nursing partnered with two local community centers to develop lay advisory boards of community members who are not prominent community representatives. The Lussier Community Education Center and Goodman Community Center have served their neighborhoods for over 30 years, offering programs and services that reflect the diversity of their communities. In 2010, we worked with staff at the community centers to submit a proposal for a program grant to the National Institutes of Health (NIH). We received a 3-year grant to establish a sustainable infrastructure to link community members with researchers to improve the quality of health sciences research. The UW-Madison Health Sciences Institutional Review Board (IRB) designated our grant activities as exempt from review.

In one of our grant activities, we worked with the community centers to develop and pilot two lay advisory boards, the Community Advisors on Research Design and Strategies (CARDS)®. We established a CARDS group at each partnering community center. For the past 5 years, each group has met monthly with guest researchers to provide feedback on the appeal, clarity, and accessibility of materials and processes used in clinical research. Our NIH grant ended in 2013, and at the time of this writing we are sustaining the CARDS as a program within the Wisconsin Network for Research Support (WINRS), a fee-for-service community and patient engagement center supported by the School of Nursing (http://winrs.son.wisc.edu/). The UW-Madison Institute for Clinical and Translational Research, a Clinical and Translational Sciences Award site, provided additional support for the program.

The CARDS® Program

The CARDS are based in the community, so researchers often assume that CARDS input is relevant only for researchers interested in community-based participatory research (CBPR) or community-engaged research (CER). In fact, since the program's inception, the CARDS have worked extensively with researchers conducting clinic or hospital-based studies. The CARDS provide lay, patient-centered feedback on materials for any type of human subjects research, regardless of the specific research topic, setting, methodology, or study population. To date, researchers and their project staff typically attended one or two meetings for each project that they brought to the CARDS, although we placed no limit on the number of CARDS meetings that a researcher may attend. The CARDS program makes it feasible for researchers who are not conducting CBPR or CER to get timely, meaningful lay input on their research materials, without substantial investment of resources.

Program Participants

Members. For the CARDS, we wanted not prominent community representatives, but people who have been underrepresented in healthcare research (Hasnain-Wynia & Beal, 2014). We intentionally sought to recruit people who are not connected with academia, research,

healthcare, or local power structures. Unlike recruitment for many CABs, we did not establish specific inclusion criteria, such as residency in a certain neighborhood or diagnosis of a particular health condition (Stewart et al., 2015). We asked community center staff (CARDS liaisons) to recruit typical users of services at their centers. Liaisons shared an informational flyer with community members who used center services such as parenting and childcare programs, women's support groups, job clinics, food pantries, and senior meal programs. People who were interested followed up with the CARDS liaison to complete a membership application, on which they were asked to briefly explain why they wanted to be part of the CARDS. Sometimes, people who worked or volunteered at the centers heard about the program and completed applications. At the time of this writing, 15 CARDS members were participating in the program. Nine participants (60%) were women and 10 (67%) were African-American. Ages ranged from early 20s to mid-70s, and educational attainment ranged from incomplete high school preparation to post-high-school coursework.

Many CABs have expansive roles for their members that may encompass defining research agendas, providing entrée into a community (gatekeeping), engaging in the conduct of research, and providing feedback on scientific papers (Israel et al., 2005). The sole function of the CARDS is to meet monthly with researchers to review, discuss, and provide feedback on research plans and materials, including recruitment materials, data collection procedures and instruments, web-based materials, and smartphone apps. CARDS members are never required to complete work between meetings. For each 90-minute meeting, they receive a cash stipend of $35. Although it is convenient for institutions to pay board members with checks, many people in hard-to-reach populations do not have checking accounts. As one of the CARDS explained, "$35 isn't $35 if I have to pay a fee to cash the check."

WINRS and community center staff. WINRS staff provided overall management of the CARDS program. The School of Nursing employed two WINRS staff members, at a total of 1.7 full-time equivalents. WINRS staff worked on a variety of projects but together devoted approximately 0.5 full-time equivalents to management of the CARDS. Both employees had advanced degrees (MA; PhD) and had previous experience with community engagement. One employee had primary responsibility for the program, with the other providing support. The School of Nursing and ICTR provided salary support for the full-time employee, and revenues from WINRS supported the salary of the part-time employee. In addition, each community center provided a staff member who served as the center's CARDS liaison. Table 1 lists the respective responsibilities of WINRS, community center staff, and the CARDS. We paid the centers a monthly facility fee to compensate them for liaison time, room rental, child care during meetings, and transportation for members as needed. Monthly facility fees ranged from $205 to $290, depending on whether child care was provided.

Guest researchers. Since the CARDS program began in 2010, we have conducted meetings with 40 research teams representing 21 disciplines, including cardiology, family medicine, and community health, kinesiology, nursing, pharmacy, rheumatology, and surgery. We also have worked with researchers from other institutions, sometimes conducting CARDS meetings via teleconference. Nurses constitute the largest proportion of researcher teams (58%, $n = 23$) who have used the CARDS service and have included nursing faculty, doctoral students, and nurses working in community settings. Nurse researchers have brought a variety of materials and plans to the CARDS for their review and feedback, including recruitment materials (brochures, flyers, letters, scripts); study processes (recruitment plans, interview processes, website development); focus group protocols; interview and survey questions; study information sheets; and consent forms.

We sometimes have fielded inquiries from researchers who were interested in lay review of their materials but were skeptical that lay advisors who were not members of their particular target population could provide useful feedback. Materials used in human subjects research—recruitment notices, information sheets, questionnaires and other instruments, consent forms—share a common set of challenges for members of the public due to their technical language, dense presentation of information, embedded assumptions, counter-intuitive organization, and academic tone. As members of the general public with specific training on how to give feedback to researchers, the CARDS can offer a uniquely fresh perspective on research materials, no matter the specific content of the documents. The CARDS have provided useful feedback on materials for a wide range of health studies, despite having limited or no personal experience with many of the topics that researchers present. At one of our most memorable meetings, no women in the CARDS were able to attend, so five male CARDS provided feedback on a doctoral student's survey about dysmenorrhea. We introduced the survey by reminding the CARDS that we all have experience with pain and discomfort, and we asked them to think about the survey questions in the context of their personal pain experiences. Based on CARDS feedback, the student made substantial revisions to her survey.

Program Processes

Member orientation. One of the key features of the CARDS is the orientation program. Many CABs provide minimal orientation or training for board members (Albert Einstein College of Medicine, The Bronx Health Link, & Community-Campus Partnerships for Health, 2012). In contrast, the focus of the CARDS orientation program is hands-on practice with research materials. We designed an interactive group orientation to help the CARDS develop

Table 1. Responsibilities of Community-Academic Partners for CARDS® Program

Community Center Staff	WINRS Staff	CARDS®
Recruit people who use center services to participate in CARDS program	Design, deliver orientation program for new CARDS	Complete orientation to develop skills for giving feedback to researchers
Schedule community center facilities for meetings, orientations	Conduct outreach to identify guest researchers for CARDS meetings	NA
Arrange child care, transportation for monthly meetings; serve as contact person for members to confirm attendance	Meet with researchers to prepare agenda, materials for meetings; send agenda, meeting reminder to CARDS	RSVP for monthly meetings; read meeting announcement with description of research topic and materials
Participate in CARDS meetings	Facilitate CARDS meetings; take notes; disburse member stipends	Provide feedback to guest researchers at meetings
Invoice UW-Madison School of Nursing for facility fee	Write summary reports, revised materials for researchers; complete post-meeting evaluation surveys with guest researchers	NA
Problem-solve with members to address barriers to their participation	Work with liaisons, members to support participation and sustain program	As needed, meet privately with program staff to address issues or problems related to participation
Participate in program evaluation	Design and lead program evaluation	Participate in individual interviews and group discussions to evaluate program

Note. WINRS, Wisconsin Network for Research Support; UW-Madison, University of Wisconsin-Madison; NA, not applicable.

and practice the skills needed to participate effectively at meetings. Our orientation program emphasized content that is directly relevant to the work that board members will do and gives members experience reviewing and providing feedback on recruitment flyers and letters, consent forms, and focus group questions. Completion of the 2.5-hour orientation is a requirement for membership in the CARDS and provides meaningful preparation for respectful, productive interactions with researchers.

Preparation of guest researchers. Each CARDS group has met monthly at the community centers with guest researchers. Several weeks before the meeting, WINRS staff sent the scheduled researcher a timeline of steps to prepare for the meeting, along with a link to a short web-based survey requesting key information about the researcher's desired outcomes from the meeting. WINRS staff then engaged in a series of email messages and a telephone call or face-to-face meeting with the researcher to plan and prepare for the meeting.

During the planning meeting, WINRS staff and guest researchers reviewed answers to the web-based survey and discussed possible materials for the CARDS meeting. Researchers often brought their staff members and students to planning meetings and CARDS meetings. We select the materials that can be thoroughly discussed during a 90-minute CARDS meeting and develop a detailed working agenda. Without this preparation, researchers may have unrealistic expectations of how many documents can be reviewed during a meeting. During the planning meeting, WINRS staff shared advice on working with lay advisors. For example, we reminded researchers to use plain language, and we helped them prepare brief, straightforward explanations of their research interests. We also encouraged researchers to gracefully acknowledge all suggestions from the CARDS. Realistically, researchers may not want to or be able to follow certain suggestions, but thanking the CARDS for all suggestions helps CARDS feel that their voices are heard and welcomed. Decisions about how to use CARDS feedback can be made by researchers after they attend meetings, when they can decide whether to incorporate specific suggestions fully, partially, or not at all.

As part of meeting preparation, we discussed fees and payment arrangements with the guest researcher. We bundled our costs for WINRS and community center staff time, CARDS stipends, and other costs for the CARDS service into a fee of $1964, for a 90-minute meeting, preparatory work with the guest, and post-meeting summary documents. As required by the UW-Madison, our fee structure was based on a cost-recovery model; the fee for the CARDS service covered our costs for providing the service but did not generate profit. Researchers typically paid the fee with grant funds. For doctoral students or junior faculty without funding, we offered a reduced fee.

After we met with guest researchers, we sent a brief meeting announcement to the CARDS to provide information on the guest researchers, including their focus areas, materials they would present at the meeting, and type of help they would like from the CARDS. The announcement also included a personal statement from the guest researcher about why she or he cared about the research topic. We worked closely with researchers to help them craft personal statements. The CARDS have told us that learning about a researcher's personal motivations for doing research has helped them overcome their stereotypes of researchers as cold academics who use research participants to serve their own ends.

Meeting structure and practices. We have followed a structured sequence of activities at each meeting. We started each meeting with an opening question. Everyone at the meeting participated in a round-robin sharing of names and brief responses to the opening questions. Our opening questions gave everyone at the meeting a chance to share something about themselves. The activity helps to break stereotypes that researchers and lay community members may hold about each other. Over time, the sharing that occurs with the opening question helps group members establish personal connections and build a sense of community. We often crafted opening questions that were related to the research topic that we would discuss at the meeting. For example, our opening question for a meeting with a researcher studying nasal irrigation was "Please say your name, and tell us one favorite home remedy for dealing with a stuffy nose or other sinus problems."

After the opening question, guest researchers introduced themselves briefly, using plain language to explain the goal of their research and why it is important. We used the remaining 75 minutes of the 90-minute meeting to discuss the researcher's materials. The structure of the discussion was standardized and used three steps to elicit feedback from the CARDS:

1. The researcher describes how and where a prospective study participant would encounter the research materials, for example, mailed letter to a home address; flyer posted in a primary care clinic; consent form presented in a community setting; website that the participant will access from a home computer.
2. We ask guest researchers to read their materials aloud, several lines at a time, to facilitate full participation of everyone present, regardless of literacy level.
3. WINRS staff facilitate a section-by-section review of the materials. After a section is read, the CARDS offer comments. We take detailed notes and write CARDS feedback on a flip chart, a practice that helps to affirm the value of everyone's contribution to the discussion. After finishing review of one section, we move to the next section and repeat the process.

Post-meeting products and survey. During the first 2 years of CARDS meetings, we provided a summary report to researchers who attended meetings. The 1–3 page report summarized the overall feedback from the CARDS on the research materials reviewed at the meeting and highlighted specific issues related to the content, language, organization, and format of the materials. However, when researchers later shared their revised materials with us, we saw that they often did not translate CARDS feedback into concrete changes to their materials, although they rated the value of the meetings very highly. Consequently, we began to deliver revised versions of their project materials to all guest researchers, to make it easy for them to implement recommendations from the CARDS. Researchers consider and balance numerous factors when designing their study materials, and we encouraged researchers to use the CARDS-revised materials in whatever way makes the most sense for them, based on their experience and expertise. To complete our consultation, we sent a post-meeting online survey to all researchers who attend CARDS meetings to ask them to evaluate their experience.

Program Outcomes

CARDS® Insights and Recommendations

The value of the CARDS lies in their ability to provide researchers with fresh insights and feedback that academic or professional colleagues immersed in research may not be able to offer. As the concept of health literacy has permeated health sciences research, researchers have developed more awareness of how using technical jargon can undermine subject recruitment. Use of readability tools such as SMOG (National Cancer Institute, 1989) or the Flesch–Kincaid tool in word processing programs can be helpful for improving readability. Researchers also sometimes rely on colleagues, graduate students, high-level stakeholders, or IRBs to identify glaring problems in research materials. While these resources can be helpful, they may not be sufficient for ensuring that materials are acceptable and inviting to the general public. Over 5 years of monthly meetings, the CARDS have highlighted several key characteristics of research materials that may turn people away from participating in research.

Passive language. Plain language guidelines highlight the importance of using active language instead of passive language ("staff on my research team will ask you several questions" instead of "you will be asked several questions"). Passive sentences lack the clarity of active sentences because they do not clearly identify the actor. The CARDS highlighted other problems with passive language, describing it as confusing, impersonal, and evasive. For them, passive language in a research document raised questions and reservations about who is behind the research project, the true motives for the project, and what researchers will do with participants and their information. Passive language pervades consent forms, and it particularly troubled the CARDS when it appeared, as it does routinely, in material related to privacy and confidentiality. Vague assurances that "your information will be stored in a secure location" aroused their suspicions; they wanted to know exactly who would take responsibility for protecting their information.

Specialized use of everyday language. The CARDS provided feedback of a nuanced nature that highlights issues not measured by readability tools. The CARDS repeatedly pointed out things that were confusing, patronizing, or even offensive or frightening to potential research participants. For example, even though researchers may scrupulously avoid using technical jargon, they

often use everyday language in a highly specialized manner. The CARDS said that words such as "data," "procedures," "health outcomes," "technique," and "investigate" sounded ominous or threatening. Even the word "study," universally used by researchers in recruitment materials, can evoke images of being subjected to dangerous tests or used like a guinea pig. The CARDS strongly preferred "project" as a non-threatening alternative. When referring to research subjects, the CARDS strongly preferred the phrase "project participants," which sounds inviting, inclusive, and less scary than the off-putting, objectifying "subjects." Table 2 lists additional examples of how the CARDS interpreted common research language.

When we met with researchers to prepare for CARDS meetings, we explained that the CARDS may occasionally suggest alternative language that an IRB will reject. To our knowledge, these instances were infrequent and did not limit the value of the service. At the time of this writing, we were collaborating with an IRB workgroup that is charged with improving templates for informed consent. The working group has attended three CARDS meetings to learn the kinds of information about research that are important to the non-academic community and to help craft clearer language for consent documents. In the coming year, the working group expected to pilot new templates that incorporate CARDS feedback.

Perceived tone of documents. The CARDS noted several other key considerations for making documents accessible and inviting. The overall tone of a document can serve to engage or disengage potential participants. For example, although best practices in health education often recommend repeating key messages in documents, the CARDS said that redundant language feels insulting, by implying that they are not smart enough to understand something the first time that it appears in a document. In addition, materials that sound non-judgmental may be more likely to engage potential participants, especially for studies that address health behaviors. The CARDS often used the term "gentler" when recommending alternative language. For example, when researchers asked about tobacco use, the CARDS noted that the simple question "Do you want to quit smoking?" is a complex, sensitive question, and that asking a "yes" or "no" question may not be appropriate. The CARDS suggested, "Are you thinking about cutting back or quitting?" as a gentler alternative that raises the smoking issue without provoking defensiveness by implying that the person is doing something wrong.

Requests for demographic information. Demographic questions are standard items in many research instruments, and members of the public also frequently encounter them in the context of consumer research or participation in various programs. Despite the ubiquity of demographic questions, they may provoke negative reactions due to their highly personal nature. The CARDS told us repeatedly that they expected

Table 2. What Researchers Say, What CARDS® Hear, and What CARDS Recommend

What Researchers Say	What CARDS Hear	What CARDS Recommend
My colleague is the PI on this study.	I work with a private investigator who will poke into your personal business.	I work with Xxx Xxxx. (S)he is the lead researcher on this project.
Data will be collected about your lifestyle.	We will violate your privacy and make judgements about your personal life.	My research team will ask you some questions about a typical day for you.
Participants will take part in several procedures.	Participants will have scary, invasive medical acts performed on them.	Participants will be involved in several activities, including. . .
We will monitor your progress during this study.	We will track you with something like an electronic ankle bracelet during this study.	We will keep in touch with you during the project.
This study will test an experimental technique for treating sinus infections.	You will be a guinea pig for something dangerous, untried, and invasive.	This project will test a new way of treating sinus infections.
We would like to include your name in our study registry.	We want to put your name on a registry, like a sex offender registry!	We would like to add your name to a list of people who might like to be part of future projects.
Your input will contribute to the design of an intervention to support couples in parenting their babies.	You will help the research team confront couples who are having problems with parenting.	Your input will help us develop a new program to support parents as they care for their babies.
This study aims to improve how we provide care to people with type 2 diabetes.	Being in this study will improve your diabetes care.	We would like to hear about your experiences to help us figure out how to improve care for people with type 2 diabetes.
We will consider your individual home environment and search for assessable risks for falls.	We will judge you and your home and snoop into your personal belongings.	We will use a checklist to look for risks that you can change to prevent falls.
To manage your blood pressure, be more active and drink less alcohol.	We assume that you are not active and that you drink too much.	To manage your blood pressure, be active and limit your intake of alcohol.

researchers to use demographic information to stereotype people and present them in a bad light. The CARDS shared personal stories about skipping demographic questions, providing false answers, or declining to complete an instrument altogether if it includes demographic questions. They recommended that researchers ask only those questions that are critical for answering the study questions. In addition, the CARDS recommended that researchers provide a short, straightforward introduction to demographic questions to explain why the researcher needs the requested information. Explanations that simply invoke grant requirements for demographic information may be insufficient and potentially offensive; rather, a thoughtful explanation for asking demographic questions can explicitly acknowledge that demographic questions are personal and offer a straightforward rationale for asking them.

Lessons Learned on Engaging Hard-to-Reach Groups

When we initiated the CARDS program, we deliberately sought participants outside of the academic environment and not situated in positions of power. Our community center liaisons intentionally recruited people not typical of advisory boards. Many of them had had challenging life experiences, including poverty, homelessness, long-term underemployment, and chronic health problems. We structured the CARDS program to minimize barriers to participation and to demonstrate our respect and appreciation for all members.

Our use of conscious practices that engender trust and help people feel valued helped us to achieve outstanding retention of our lay advisors. Six of the current members (40%) have participated from 2010 to the time of this writing, and the remaining nine members had participated since 2012. Half of the former members who dropped out of the groups from 2010 to 2012 ($n = 6$) left because they moved out of the area, changed their work schedules, or experienced re-incarceration. Attendance has been very consistent. Since 2013, when we standardized many of our meeting processes, aggregated attendance for the program has been 81% (486 instances of member present for meeting/601 total opportunities to attend). Attendance for individual CARDS over this period has ranged from 58% of meetings to 97%.

Consistent staffing at both WINRS and the community centers has been a critical component of developing trusting relationships with our members and retaining them in the group over time. The same WINRS staff have facilitated every CARDS meeting from 2010 to the time of this writing, and the CARDS liaisons typically have stayed in their positions for at least 2 years. Consistent staffing helped us to develop trusting, long-term relationships with our members, which in turn supported honest dialogue and problem solving with members when challenges arise. On several occasions, we met with individual CARDS to address problems related to inappropriate behavior toward a program participant or insufficient participation in meeting discussions. The orientation that all CARDS complete served as a useful point of reference for constructive discussions about performance and expectations.

During our first few years, we often wrote short individualized notes to send to the CARDS after meetings, to thank them for their contributions. We called these notes "affirmations" because they affirmed something unique and positive that the person brings to the group. We also have held annual celebrations with the CARDS. Our celebrations have included meals, holiday treats, and small tokens such as gift cards.

For some of our members, applying for jobs is a frequent and difficult task. We have provided tangible support with letters of reference and assistance with resume writing. We have written letters of reference for members based on their work with the CARDS and provided resume templates that highlight the unique skills and tasks of the CARDS. With the advent of web-based systems for providing references, we have also completed on-line surveys to support job applications for some of the CARDS.

Program Evaluation by the CARDS®

In 2014, we completed a program evaluation with the CARDS. We conducted separate focus groups at each community center to explore members' opinions and attitudes in four areas: their orientation to the program; their work at CARDS meetings; factors that contributed to their retention in the program; and changes in how they viewed research and researchers. The CARDS valued the orientation and particularly emphasized the impact of group training activities on communicating respectfully and giving effective feedback. They also appreciated the orientation as a chance to experience what they would do at meetings, and several members credited the orientation with giving them confidence that they could do the job. The CARDS described multiple characteristics of the monthly meetings that make the work meaningful and enjoyable. These included learning about research topics that were relevant to them and their community and having a chance to give advice directly to researchers.

The most prominent theme throughout the focus groups was the sense of community that motivated the CARDS to stay in the program. They used words such as respect, good will, support, camaraderie, and fellowship to explain why they stayed in the program. They also described how our standard meeting practices such as the opening question, use of the flip chart, meeting snacks, and non-hierarchical facilitation contributed to a sense of community. Another major factor related to retention was the sense of service to others. As one

member said, "I like being able to help others. We may be helping folks who will never even know we helped them." Finally, the CARDS discussed how their attitudes toward research and researchers have shifted. They said that the opportunity to work regularly with researchers had helped them respect researchers, rather than mistrust their motives. Some CARDS also indicated that they were more interested in participating in research themselves: "Now I feel it's important to participate in research. Researchers are doing it for the community; it's bigger than just one person."

Researchers' Evaluation of CARDS® Service

Since 2012, all guests who attended CARDS meetings received an email 1 week after the meeting inviting them to complete a brief web-based evaluation survey. To minimize the response burden on researchers, the survey included just a few key questions to assess guests' satisfaction with the overall CARDS service, including premeeting preparation, and post-meeting reports. Guests at CARDS meetings rated the service very highly. Ninety-seven percent ($n = 70$) of survey respondents indicated that they felt sufficiently prepared by WINRS to meet with the CARDS. Guests typically brought one or two items for review, and they most frequently brought data collection materials such as survey or focus group questions (51% of researchers, $n = 37$) and recruitment materials (37%, $n = 27$). A large majority of guests (90%, $n = 65$) planned to change their materials based on CARDS feedback. (Several respondents self-identified as project staff that did not have authority to make changes to research materials.) Ninety-nine percent of survey respondents ($n = 71$; 1 missing response) indicated that they would recommend the service to colleagues. Table 3 displays findings related to guests' perceptions of the utility of the CARDS program.

When we initiated the program, we wondered whether regular contact with researchers would acclimate the CARDS to research language and over time diminish their value to researchers. To preserve the lay perspective of the CARDS, we have maintained a schedule of meeting only once monthly at each center. Researchers' evaluations of the CARDS service have been favorable across the lifespan of the program, suggesting that the CARDS have continued to offer valuable feedback. Findings related to tests of a target population's response to the CARDS' recommended changes in research materials are published elsewhere (Bowers, Jacobson, & Krupp, 2016).

Table 3. Guests' Perception of Utility of CARDS® Services, 2012–2016 ($N = 72$)

Which Services of the CARDS Program Were Particularly Useful?	*n*	%
Completing web-based survey to initiate planning	28	39
Meeting with program staff[a]	44	61
Presenting ideas and materials to CARDS	56	78
Getting feedback from CARDS	70	97
Receiving summary of CARDS feedback	65	90
Receiving revised study materials	60	83

Note. Percentages do not sum to 100% because respondents could select multiple options.
[a]New question added to survey in 2103.

Conclusion

Health sciences research should serve everyone. When researchers have study participants who reflect the rich diversity in our communities, our society has a real chance to develop policies and practices to eliminate health disparities. But current research suggests that equitable representation of diverse groups in research has yet to be achieved (Bonevski et al., 2014). Social justice is a central concern of the nursing profession, and nursing research literature includes numerous examples of studies using approaches such as CBPR to engage disenfranchised or hard-to-reach stakeholders in the research process (e.g., Perry & Hoffman, 2010; Stacciarini et al., 2011). In addition, many nurse researchers have designed or implemented interventions with input from community health workers or promotores (e.g., Nies, Troutman-Jordan, Branche, Moore-Harrison, & Hohensee, 2013; Whittemore, Rosenberg, Gilmore, Withey, & Breault, 2014).

The CARDS represent a new, unique model for engagement of people who are not prominent community representatives in the design of research. The model offers distinct advantages over other forms of public engagement. Although lay stakeholder engagement can take diverse forms, sometimes it can seem as if the options are all or nothing—either researchers conduct CBPR or they do nothing to seek community input. The CARDS model makes reaching hard-to-reach stakeholders feasible and convenient for researchers. The CARDS bring hidden voices into the research enterprise and make these voices easily accessible to researchers. CARDS is an innovative model for nurse researchers to support sustainable, meaningful engagement of hard-to-reach populations in research planning and activities; increase the diversity of groups represented in research studies; and ultimately help to reduce health disparities.

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The Power of The Personal: Breaking Down Stereotypes and Building Human Connections

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On a weekday night, every month, twelve people meet around a table at a community center in Madison, Wisconsin. The group includes people who are homeless, previously–incarcerated, unemployed, handling chronic mental or physical challenges and several health science researchers. Someone walking by the room might notice the intense energy, lively debate, engaged participation, reams of flip chart paper, and wonder, "What's going on??"

This has been our reality every month for over six years. The people *giving* advice are the Community Advisors on Research Design and Strategies (CARDS)®, community members from diverse racial, socioeconomic, and educational backgrounds. The people *getting* advice are researchers who want candid feedback about how to make their materials more engaging, easier to understand and more actionable from people often labelled "hard–to–reach." And the people planning the meetings are our staff with the Wisconsin Network for Research Support (WINRS), a patient and community engagement resource.

We started the CARDS® in 2010 as a partnership between the University of Wisconsin–Madison School of Nursing, Lussier Community Education Center, and Goodman Community Center. With initial funding from a 3–year National Institutes of Health grant, our project was a response to the painful reality of persistent health disparities in our country and to the fact that health sciences research has not successfully engaged the full breadth of our country's wonderful diversity. What's the connection, we wondered? How can research appeal to a broader group of people? If all Americans did participate equally in health sciences research, would this move the needle on health inequality? With our community partners, we deliberately recruited CARDS® from groups of people most affected by health disparities and least represented in research projects. We provide an interactive orientation for all CARDS® and pay members for each meeting they attend. We also compensate the community centers for staff time and meeting space.

In the process of bringing unheard voices into the research enterprise, we have learned a lot about how to revise research activities and materials to engage a broader audience. We've also learned some interesting things about the stereotypes and assumptions that researchers make about "hard to reach" people, the assumptions that lay people make about researchers, and how to overcome prejudices that make it hard to connect with each other.

What are some common researcher assumptions? "I've spent my whole professional life researching this disease, what can I learn from people who don't really know anything about this topic?" "I know what I will get—people telling me to 'dumb down' my materials." "The feedback I

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get from colleagues is sufficient." And community members have their own pre–conceptions: "I think research projects are a scam. Researchers have a hidden agenda and just are trying to help themselves." "Lots of researchers are white—they don't want to hear my ideas." "Research? Nope, I don't want to be a guinea pig!" "Most researchers are uppity and just talk down to us." And these are just the comments conveyed to our WINRS team directly. Obviously, other prejudices and stereotypes also divide us—based on how we dress, talk, our skin color, the condition of our teeth, etc.

Imagine trying to communicate in a room where these two worlds collide. On one side: I see you as less educated, less smart, and not able to offer me anything useful. On the other: I see you as sneaky, self–interested, arrogant and out to take advantage of me. How do we find common ground? How can researchers get the advice they need to make their projects more accessible, appropriate and engaging? How can we create a space where lay people feel free to share important feedback?

Two specific practices we use to break down divisive assumptions and stereotypes demonstrate the power of "The Personal." The first practice is to start each CARDS® meeting with an opening question that everyone at the meeting answers. This may seem straightforward, but learning what makes an effective opening question has been an experience of considerable trial and error.

At one meeting, the guest was a young researcher who appeared very stiff and ill at ease at the outset. Our opening question was: "Think about a time when you took care of someone else—a child, relative or friend. Tell us what made you good at taking care of that person?" As we went around the room, we heard from a woman caring for her grandma, who described the patience (and humor!) required to deal with increasing forgetfulness. We heard about stepping up to be on call 24/7 for an ailing friend and making the decision to move in with aging parents. When it was the researcher's turn, she started by simply holding up her hands. People shifted uncomfortably in their seats, wondering if she was giving up on the meeting before it had even started. Then she spoke: "I have 3 young children," she said gently. "I've always felt like human touch is one of the most caring gifts we can give each other. Every time I bathe my kids, wipe their noses or their tears, wash a scrape . . . touching them in a tender, loving way seems like one thing that makes me good at taking care of them." By the time she finished this very short statement, there were plenty of damp eyes and warm smiles around the table, and we were all looking at each other with a very different perspective. The power of "The Personal."

At another meeting, we asked, "Looking back on your childhood, what is one *good* memory that really sticks with you?" One of our CARDS® has struggled with drug addiction and shows many of the physical ravages of this difficult history. It would be hard for most people to look at this person and not jump to conclusions based on outward appearance. When it was his turn to answer the opening question, he said: "I grew up in New York. I had the best granny in the world. Every year, she got me all dressed up and took me to see the Christmas show with the Radio City Rockettes. Every single year! She said I would never miss a Rockettes Christmas show—and I never did." The impact on the researcher (and the rest of us) was amazing. To see him glow with this happy memory and to unexpectedly glimpse the excited, dressed–up little boy still inside this grown man was transformative. The power of "The Personal."

But not just any opening question works! Here are some lessons we've learned.

Some opening questions are simply boring, and do not help us connect with each other. When we had dementia researchers at a CARDS® meeting, we said, "Tonight we are going to talk about research on memory. What is one trick you have for remembering or keeping track of things?" Not surprisingly, the answers were all basically identical: "I write lists." "I have a special place where I put important things, like my keys." No one shared anything uniquely personal—so no personal connections were established and no stereotypes were really challenged.

We've also learned that while "The Personal" is powerful, it needs to be used thoughtfully. Some opening questions can unintentionally derail the

group with negative energy, making it harder to get on a productive track. One night we said, "We are going to talk about home care after surgery. That got us thinking about scars—we all have scars from accidents, injuries or wounds. Please tell us a story about one scar you have." Although we prepared a staff member to model a light-hearted memory of a scar she got while playing with her beloved baby sister, the following stories took a darker turn. We heard about a stillborn baby, injuries from the Vietnam War and serious work–related accidents. Soon the group was extremely somber, with a palpable sadness around the table created by stories that led us into our own separate worlds of grief.

Lesson learned—craft a thoughtful opening question likely to draw out stories and experiences that engender positive emotions and reinforce human connections. This not only helps us to see past the stereotypes and assumptions that divide us, it also reduces our own barriers of discomfort, nervousness and feeling out of place. It's hard to connect with a stereotype. It's hard *not* to connect with a good personal story. As one of our CARDS® told us, "I love the opening questions. They help us accept the researcher. When we share life experiences, we see each other as human."

The second personal practice that breaks down stereotypes is using five minutes of meeting time for guest researchers to explain their personal motivation for their research. The CARDS® have repeatedly told us how critical it is to understand why a researcher is focused on a specific topic: "Are they just doing this for the money or do they actually care about this problem?" The fundamental truth we've learned is "people don't care how much you know until they know how much you care." However, when we first started asking researchers to comment on what motivates them to do their research, they generally discussed "gaps in the literature" or the "iterative nature" of the research process. Researchers are trained to be objective and scientific—not to talk from the heart when discussing their program of research. But we have found that with some individualized coaching, researchers of all kinds can benefit from the power of "The Personal."

Now we specifically ask researchers to reflect on why they are passionate about their research and to answer this question in a short survey before coming to a CARDS® meeting. We follow up with each researcher and together prepare a short "script" for the researcher to share at the meeting—expressing in 2–3 sentences why they have a personal stake in their research topic. Consider the difference between "I'm part of a multidisciplinary team facilitating innovative science, targeting the prevention and treatment of this disease with novel research projects . . ." versus "This research is important to me because of my own family history with this disease. I am personally committed to making a difference in the prevention and treatment of this disease." OR "I focus on this research because scientists still don't understand the most cost–effective way to treat this condition . . ." versus "I am a physician who treats people with this condition. I have seen my patients struggle with both the terrible symptoms of this disease and with the high costs to treat it. I hope what we learn in this project will help my patients and the many others whose lives are damaged by this condition."

Some of the most poignant comments we have heard in evaluations with the CARDS® are about how their attitudes towards researchers have shifted as a result of the power of "The Personal." As one of the CARDS® put it, "I get really moved when researchers tell us why they study what they do—the stories of grandparents, other family members, patients and so on. You can see that they genuinely want to make the world a better place." Another said, "I used to think that researchers were 'off in another universe,' but now I see them as decent, caring human beings who are trying to do good things."

Researchers also have shared touching comments about being able to connect with these "hard to reach" people: "The single best thing about meeting with the CARDS® was getting feedback from community members we normally wouldn't have the opportunity to talk with." "Getting advice from people with 'lived experience' is more critical than we realized. Many researchers don't consider the perspective of participants. I really didn't

think about this issue seriously, but this meeting improved my materials *and* changed my attitude!"

These two practices, thoughtfully and consistently followed, enable us to harness the power of "The Personal"—breaking down barriers and building human connections that empower all stakeholders to participate in reducing health disparities and improving health outcomes for everyone.

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Sample Agenda

90-minute Stakeholder Meeting

- **Location**
- **Date**
- **Time**

Item	Lead	Time	Purpose
Welcome/Announcements		**2 mins**	• Welcome • Good time to turn off cell phone • Review meeting tips • Other announcements as necessary
"Close the Loop"		**3 mins**	• Show impact/value of stakeholder input • Demonstrate transparency/ honesty in how input is being used
Opening Question/Intros		**10-15 mins**	• Get everyone talking/engaged • Use a question related to content of meeting, if possible • Focus on assets of all participants
Research Overview		**5 mins**	• Provide brief introduction to researcher/research topic • Offer insight into researcher's personal interest in topic • Help stakeholders personally connect with researcher

<u>Group discussion</u> **"Set the Stage"**		**5 mins**	• Help focus stakeholders to give relevant feedback • Provide key info, such as: ○ <u>Who</u> is the audience? Who will see the material/ document (age, etc)? ○ <u>Where</u> will they be when they see it? (at home alone, in an appointment with a health care provider) ○ <u>What</u> does the research team want the target audience to DO as a result? What is your goal for this material? ○ Any other key information?
Review Materials		**60-70 mins**	• Go through the materials section by section, reading each section aloud and asking for feedback. • Ask questions such as: ○ What are your first impressions? ○ Does this make sense? ○ Is it clear, easy to understand? ○ It is engaging/interesting? ○ Is any important information missing? ○ Is anything confusing, off-putting, scary or offensive? ○ How can this material be improved?