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Linking Practice-Based Research Networks and Clinical and Translational Science Awards: New Opportunities for Community Engagement by Academic Health Centers

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Abstract

Purpose—Practice Based Research Networks (PBRNs) are a part of many National Institutes of Health (NIH) funded Clinical and Translational Science Award (CTSA) sites. PBRNs, groups of primary care practices committed to collaborating on practice-relevant research, are unfamiliar to many CTSA leaders. Conversely, the CTSAs, as new research structures designed to transform clinical research, are unfamiliar to many PBRN Directors. This study examined the extent to which these programs have congruent goals and expectations, and whether their engagement is likely to be mutually beneficial.

Method—The authors sent a web-based survey to 38 CTSA Community Engagement Directors and a similar survey to 114 PBRN Directors during Fall 2008.

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Results—The investigators received responses from 66% (25/38) of CTSA Community Engagement Directors and 61% (69/114) of PBRN Directors. Two-thirds of responding CTSAs reported working with PBRNs and over half of responding PBRNs reported a CTSA affiliation. Both groups indicated this relationship was important. CTSAs looked to PBRNs for access to patients and expertise in engaging communities and clinical practices. PBRNs reported seeking stable infrastructure support and greater collaboration and visibility in the academic research community. PBRN infrastructure support from CTSAs was highly variable. Both groups perceived considerable promise for building sustainable relationships and a bi-directional flow of information and research opportunities.

Conclusions—With less than three years of experience, the PBRN/CTSA relationship remains in the discovery phase, and the participants are still negotiating expectations. If these collaborations prove mutually beneficial, they may advance the community engagement goals of many academic health centers (AHCs).

The National Institutes of Health (NIH) Roadmap initiative has made clinical and translational research a priority. Translational research is supposed to improve the application of scientific discoveries from the “bench” to actual patient care at “the bedside” and to facilitate the bidirectional development of research questions.[1] Over the past decade, community engagement has become an increasingly important component of medical research and it is described as an essential component of the current NIH Roadmap.[2] In 2006 the Clinical and Translational Science Award (CTSA) program was implemented to accelerate the translation of research into the community to improve population health.[3]

The CTSA program describes a vision to improve the conduct of biomedical research, reduce the time required for laboratory discoveries to become routine care, engage communities in clinical research, and train the next generation of clinical and translational investigators.[4,5] The CTSA consortium, which began with 12 awards in 2006, now includes 39 academic health centers (AHCs) in 23 states. NIH funded fourteen new CTSAs in 2008 and one has been added in 2009. The fully implemented CTSA program will include 60 funded institutions by 2012.[3] Recent cuts to funded CTSAs from the NIH have raised concerns regarding the capacity of CTSAs to transform the academic research model.[6]

The interest in community/academic partnerships as a means of improving population health through clinical research is high.[7,8] Reaching and involving communities in research is a CTSA priority, and each center must include a Community Engagement core component. Many CTSAs included Practice-Based Research Networks (PBRNs) in their grant proposals, usually incorporating them as part of Community Engagement. PBRNs are groups composed mainly of primary care clinicians committed to collaborating on research about issues relevant to routine care delivery.[9] Examples include the delivery of preventive health services such as colon cancer screening and the provision of evidence-based treatments for chronic diseases such as diabetes and depression.

PBRNs in the United States have existed since the 1970's, with considerable growth since 2000 when the Agency for Healthcare Research and Quality (AHRQ) began providing small amounts of infrastructure funding and established a PBRN Resource Center.[10] A 1994 description of PBRNs noted that 28 primary care PBRNs were active in North America.[11]

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By 2004, the PBRN Resource Center identified 111 active networks in the United States.[12] Many wonder how the CTSA program will affect the development and growth of new and existing PBRNs.

Primary care PBRNs have typically invested substantial time and resources to develop long-term relationships with clinicians, their practices, and their communities. In general, practitioners are motivated to participate in PBRNs with the goals of improving the quality of care in their practices and improving community health.[13] These PBRN “laboratories” have been identified as a key opportunity for enabling translational research.[14,15]

Maintaining infrastructure support remains a struggle for most PBRNs.[16] Core network elements include a director, one or more coordinators, a 2-way communication mechanism among member practices, a member roster, periodic meetings and a governance structure. Estimates place the cost of this infrastructure at $70,000 annually for a basic network and $288,000 for a moderate-complexity network.[16] Most PBRNs have less than basic network support, often depending on the support of university departments of family medicine with a large contribution of volunteerism. Research grants typically cover study costs without funding PBRN infrastructure.

With the announcement of the CTSA program, there was considerable interest among PBRNs in participating,[17,18] and the CTSA network now encourages each CTSA to partner with at least one PBRN. However, the degree to which PBRNs participate in their funded CTSAs and CTSA proposals is unknown. Likewise, it is unclear how aware CTSAs are about the presence and attributes of PBRNs at their institutions, or whether CTSA and PBRN expectations are congruent. The impetus for our survey was a strong interest regarding the relationship between PBRNs and CTSAs, recognizing the potential both for tension and for mutual advantage.[19] The primary care research community discussed this relationship at the 2006 North America Primary Care Research Group (NAPCRG) annual meeting and the Annual Agency for Healthcare Research and Quality (AHRQ) PBRN Research Conference in 2007 and 2008. As another sign of interest, the NIH National Center for Research Resources awarded a supplement grant to the University of Washington CTSA to study leveraging the expertise of established network organizations -- the HMO Research Network (HMORN) and the collective PBRNs -- to move translational research into day-to-day practice.

Therefore, we sought to investigate the perceptions of CTSA Community Engagement Directors and PBRN Directors about existing relationships and their configurations. The primary goal of our study was to describe the current relationships and the perceived potential for PBRN and NIH CTSA collaboration. Our specific aims were to (1) identify expectations of each group toward the other, (2) quantify the levels of financial support PBRNs receive from CTSAs, and (3) determine the degree of tension or congruence related to the source of research topics and relationships between academic investigators and practicing network clinicians. The results of our survey study inform the general clinical research community about these innovative “laboratories” for translational science. We report here the survey results from directors of the PBRNs and CTSA Community Engagement programs.

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Methods

Selection of participants

We invited PBRN Directors and NIH-funded CTSA Community Engagement Directors to participate in this web-based survey. We selected CTSA Community Engagement Directors rather than CTSA Principal Investigators (PIs) because we thought the former would have greater awareness of PBRN functions and greater motivation to participate in the study. The authors identified CTSA Community Engagement Directors through the list of 50 voting members from the CTSA Community Engagement Key Function Committee. We removed the names of 12 NIH employees from the initial voting member list and cross referenced the remaining names with the 38 CTSA sites funded as of October 2008. We obtained e-mail addresses for the 38 CTSA Community Engagement Directors by reviewing the CTSA Community Engagement Key Function Committee e-mail listserv and through online searches.

Initially, we identified 124 eligible PBRN Directors by cross-referencing multiple sources, including the AHRQ PBRN Resource Center Inventory and the Federation of Practice-Based Research Networks (FPBRN) Inventory. Corrections to the initial list following the first online e-mail invitation resulted in a total of 114 unique PBRN Directors who were eligible to complete the online survey.

Survey administration

Separate web-based surveys consisting of both open-ended and fixed-response questions were prepared for the CTSA Community Engagement Directors and the PBRN Directors using Survey Monkey [Ref: www.surveymonkey.com]. The CTSA Community Engagement Director Survey consisted of 20 questions exploring PBRN/CTSA relationships, support characteristics, and expectations. Instructions directed the CTSA Community Engagement Directors with no PBRN affiliation to 5 informational questions at the survey's end. The PBRN Director Survey consisted of 24 questions exploring similar topics. PBRN Directors not associated with a funded CTSA or a CTSA planning grant skipped to 5 informational questions at the survey's end.

During a two-week period from October 3, 2008 to October 17, 2008, we sent an initial e-mail to each CTSA Community Engagement Director and PBRN Director explaining the study premise and providing a link to the online surveys. We made an effort to contact all eligible individuals by sending a second e-mail invitation during this two week period to all non-responders. We asked respondents to voluntarily enter their names and affiliations for response tracking purposes on the online site. We removed this personal information from responses prior to data analysis. The only incentive provided to the participants was the opportunity to receive a summary of the survey results. The Oregon Health & Science University (OHSU) Institutional Review Board approved this study.

Analysis

We downloaded data from the online web surveys into Microsoft Access for data cleaning and analysis. Analysts cleaned the quantitative data to eliminate duplicate respondents,

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incomplete responses, and inappropriate survey entries, and then calculated descriptive statistics using Microsoft Excel.

We transferred qualitative response data to Microsoft Word for coding and thematic analysis. Grounded theory[20,21] was used for identifying qualitative themes, and data coding occurred through iterative processing. The five authors initially coded qualitative responses independently. They then met at their respective university sites (OHSU and Case Western Reserve University) to reconcile individual codes and finally met as a unified group to discuss and reconcile the key emergent qualitative themes. This iterative process and triangulation by multiple analysts is an important source of rigor in qualitative research, and helps to assure the robustness and trustworthiness of the themes that emerged from this iterative process.[22–25]

Workshop on PBRN/CTSA linkages

We presented the preliminary survey results at a workshop titled “Aligning Experience, Expectations, and Resources – PBRNs and CTSAs” during the 2008 NAPCRG annual meeting. NAPCRG is a multidisciplinary organization for primary care researchers. Its goals are to serve as an incubator for new ideas, increase research capacity, and link primary care research with education and patient care.[26]

All of the study authors developed the workshop agenda and four authors (LF, MD, RD, JW) participated in the workshop session. The lead author (LF) facilitated discussion at the workshop. The published workshop objectives were to describe how PBRNs can function effectively within CTSAs to facilitate translation of research into practice, generation of new knowledge, engagement of the broader community in research, education of students, and mentoring of new clinical and health services researchers. Our workshop goal was to inform attendees of our preliminary survey findings regarding CTSA and PBRN relationships. At the start of the workshop all participants received a two-colored reversible head-band as a way to identify their primary affiliation with a CTSA, PBRN, or with neither. Two authors, one primarily associated with PBRNs (JW) and the other with the CTSA Community Engagement Program (RD), presented the quantitative and qualitative results from the survey, then asked participants to respond to the findings in terms of their own experience. The overarching question posed to workshop participants was “How can PBRNs and CTSAs maximize their opportunities for collaboration to achieve their unique (and/or complementary) goals?”

Results

Among the 38 CTSA Community Engagement Leaders, 25 (66%) responded, and of 114 identified PBRN Directors, 69 (61%) responded. We identified start-up dates for 24 CTSAs with 6 funded in 2006, 8 in 2007 and 10 in 2008. For the 64 PBRNs providing start-up dates, over two-thirds (69%) were established prior to 2005. We selected 2005 as a cut-off point to differentiate new PBRNs (established after the initial CTSA initiative) from more established PBRNs with longer track records of community and practice engagement.

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Table 1 describes results from the fixed-response survey questions to CTSA Community Engagement Directors and PBRN Directors. Responses were generally complementary; although CTSA leaders reported providing greater financial support than PBRN Directors reported receiving. The reported infrastructure support provided to PBRNs was highly variable. Because we maintained anonymity in analyzing the data, we could not match individual PBRN Director responses with those of their associated CTSA Community Engagement Directors to assess congruence. Both leadership groups reported an impact of the recent cut to the NIH CTSA awards on financial support for PBRNs.

Table 2 shows a summary of responses to open-ended questions about what CTSAs and PBRNs want from each other. Qualitative survey responses showed that CTSAs see PBRNs as an important tool and partner in moving research into the community. The key themes identified from these responses indicated that PBRNs provided opportunities for: (1) access to study participants and community research settings by CTSA investigators and (2) improved connections between the university and the community. Respondents perceived that CTSAs assisted PBRNS by providing opportunities for: (1) infrastructure support and (2) enhanced collaboration and visibility with university researchers and the university mission.

Access to study participants and communities for research

PBRN Directors reported that the CTSA wanted them to provide a community-based "laboratory" through improved access to patients, populations, and sites for research. Typical responses by PBRN Directors stated the CTSAs wanted:

- "Access to community-based clinics for a generalizable patient population - improving translation of research into practice by involving community practices in generating evidence from clinical studies to inform evidence-based medicine."
- "To be able to recruit patients with specific conditions for RCTs [randomized control trials]."

Connecting to community

PBRN Directors and the CTSA Community Engagement Directors also emphasized that PBRNs provided more than just expanded access to research participants--PBRNs also presented opportunities for the academic institution to build relationships with the community. One PBRN Director stated:

- "Many folks in the [CTSA] think of PBRNs as a source for patients. However, there are many others who really see the PBRNs as the 2-way conduit for translational research, community engagement at the local level, and a true scientific conversation."

PBRN and CTSA Community Engagement Directors perceived similar opportunities regarding the PBRN's ability to initiate bidirectional exchanges that would facilitate participatory and translational research.

- "Our local CTSA looks to our PBRN for help with `community engagement', continuing our work with practicing clinicians in our region. To a lesser extent,

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they also see the PBRN as a tool for university based researchers." [PBRN Director]

- [The CTSA wants the PBRN to help with] "Engaging primary care providers to become champions for community-based research beyond the traditional academic sector." [CTSA Community Engagement Director]

Infrastructure support

When asked what the PBRN wants from the CTSA, typical PBRN Director responses were:

- "Stable infrastructure support for network staff to assist with study proposals, communicate with clinicians and practice staff - input on the type of studies the CTSA wants conducted within a PBRN."
- "Support of research initiated with and by community clinicians to benefit community-based patient health issues."

Community Engagement Directors were supportive of providing PBRN infrastructure resources, but were limited in what they could do given the CTSAs' varied constituents and competing demands.

- "Stable funding for PBRN infrastructure is an ongoing challenge. Published productivity from PBRN projects should increase. More investigators need to be aware of the opportunities in the PBRNs."
- "They [PBRNs] represent one aspect of community engagement …. We have other components that are involved in partnerships with communities, public health, health systems and hospitals that complement [the affiliated PBRN]. We see community engagement as a spectrum from investigator initiated, to practice group, to community initiated research. Our role is to be responsive to all those components."

Collaboration and visibility

The PBRN and CTSA leadership communities voiced a desire to collaborate and contribute to the mission and success of each organization. PBRN Directors expressed a desire for "improved interactions with university researchers as they try to reach out to the community" and to work with the CTSA "*in partnership for clinical translation*." One PBRN Director captured this sentiment by stating:

- [The PBRN wants the CTSA]"To understand research in primary care and how it can benefit the CTSA grant, advance knowledge, and contribute to the overall research excellence at the institution."

Some Community Engagement Directors echoed these sentiments for enhanced collaboration by providing examples:

- [The CTSA played a role in] "Helping them [the PBRN] fit within the larger institutional mission. That is, both the PBRNs and the Community Engagement core are parts of the larger mission of improving health of our communities - and we need both."

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- "The CTSA made the PBRN more robust, more widespread geographically and conceptually, and has brought it from the Department of Family Medicine into the medical school."

A sub-theme regarding collaboration was that CTSA/PBRN relationships are in the early stages of development, requiring education and dialogue regarding PBRN operations, organizational structure and research capacity. PBRN Directors reported that CTSA leaders have limited but growing understanding of the importance of PBRNs to address the research needs and interests of their clinician-members. While some PBRN Directors expressed that they did not actively communicate with the CTSA leadership, many respondents were positive about future PBRN/CTSA research partnerships. Two PBRN Directors stated:

- "One of our roles is education in this area. Our CTSA leaders are very receptive."
- "We are at the very early stages, so it is too soon to provide a reasonably informed response. The institution has itself suggested that it intends to work on educating researchers."

Many respondents emphasized the need to increase awareness regarding the financial costs associated with sustaining community and clinician relationships. One Community Engagement Director stated:

- "Investigators often do not understand the true costs of engagement and recruitment. Each PBRN uses a slightly different business model, but costs can be broken down into a "dollar/person approached" figure. Investigators rarely think of recruitment costs this way, and believe sometimes that costs are too high. However, when investigators have worked independently with practices in the past and hired RA's for recruitment that are outside the PBRN, the ultimate costs are often 2–3 fold higher as recruitment takes longer and costs for individual RAs cannot be shared across studies (i.e. a PI needs to hire a full-time RA who must then travel between sites). Communicating the true costs and benefits of the PBRN infrastructure to PIs that have not recruited in primary care before is a slow and evolving process."

Workshop discussion

Four study authors (LJ, MD, RD, JW) and eighteen attendees participated in the NAPCRG Workshop. Fourteen attendees were associated with PBRNs having a relationship to a CTSA at their institution and four had no PBRN or CTSA affiliation. A majority of participants indicated during introductions that there was a need to enhance collaboration with their CTSAs. Following a detailed presentation of survey results, workshop participants engaged in a lively discussion that qualitatively reinforced our analysis of the survey data, adding to the robustness of the findings. The workshop discussion regarding survey results emphasized key concepts that were necessary for CTSA and PBRN alignment.

For example, many participants noted that connectivity and mutual education between an institution's CTSA and PBRN programs was vitally important to their success. PBRN affiliates who were aware of the time required for building relationships in their clinics and

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communities emphasized that connecting to university CTSA programs required a complementary “courting” process. Such interactions require both resources and time.

Participants discussed the need for increased awareness regarding the financial requirements of initiating both PBRN and community-engaged research. Some PBRN representatives while reporting no current affiliation or financial support by a CTSA emphasized the importance of being at the CTSA table because of its opportunities for university connectivity, community health enhancement, and future funding. Workshop participants felt the opportunity for PBRNs to integrate into the institution's developing clinical and translational research infrastructure had long-term value for the networks. Attendees also emphasized the potential value of expanding PBRNs from a focus on family medicine to include disciplines such as pediatrics, internal medicine, pharmacy, dentistry, and alternative medicine.

Discussion

Our findings suggest areas of both congruence and tension in CTSA-PBRN relationships. Both parties recognize some shared goals and opportunities for mutual advancement. At the same time, PBRN Directors generally expressed a need for greater infrastructure support from the CTSA, arguing the need for sustained relationships to maintain trust and cooperation among participating practices. They also emphasized the importance of having research topics emerge from the practicing physicians, or at least vetted by them. CTSA leaders often sought PBRNs as study recruiting sites for university investigators, but seemed less aware of the need for cultivating ongoing relationships and the importance of engaging practitioners in the support and development of study protocols. In the online survey many PBRN and CTSA respondents emphasized that their relationships were new and still in the formative stages. Participants during the NAPCRG workshop echoed this sentiment. These findings highlight the need for increased discussion regarding how PBRN and CTSAs can be mutually beneficial.

Our study had some important limitations. Response rates were 66% from CTSA Community Engagement Directors, and 61% from PBRN Directors. These response rates are typical for physician surveys, which average 54% to 61% response rates.[27,28] The likely selection bias would be to under-represent PBRNs and CTSAs that had no relationship with each other. Further, only CTSA Community Engagement Directors and PBRN Directors reporting a PBRN/CTSA association were eligible to complete all of the survey questions. Thus, the relationship between CTSAs and PBRNs may be even more provisional than that reported here. Many of the CTSAs are new, and the CTSA/PBRN relationships are not yet clear. This was explicit in some survey responses which said “*it's too soon to tell*”. We surveyed the Directors of the Community Engagement cores of the CTSAs because they, along with PBRNs, identify working with community as a key activity and may therefore know more about existing PBRN/CTSA relationships. Responses from the CTSA PIs or other CTSA investigators might have differed from those of the Community Engagement Directors because they are less closely involved in the phenomenon that we sought to study.

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Despite these limitations, this study provides an early snapshot of perceptions on both sides of a relationship that is important to the success of CTSAs and is likely to be vital to the growth and development of PBRNs. Over one-third of the PBRNs responding to this survey were established after 2005, corresponding with the first submitted CTSA applications. Tracking the evolution of this relationship over time will be important to nurturing its development and identifying successful models to translate research into practice and community settings.

Future research should identify the key attributes, organizational strategies, and methods used by exemplar PBRN/CTSA partnerships. Such studies might fruitfully investigate the views of diverse members of both CTSAs and PBRNs, including clinician members and the patient populations that translational research is designed to serve. Interested parties also need additional research regarding the optimal sources, magnitude, and allocation of funding for PBRNs, and how financial structure relates to scientific productivity. In our study, PBRN Directors described the need for stable infrastructure support as a strong motivation for linking to their respective CTSAs. Funding for moderate-sized PBRNs is substantial and highly variable.[16] Because the relationships we describe are likely to change over time for existing programs and with the addition of new CTSAs, we propose that longitudinal and descriptive research in this area is needed.

We also recommend further efforts in developing educational programs for CTSA investigators and leadership about PBRN structure and functioning, as well as participatory research methodologies. In our study, several CTSA leaders expressed a desire to learn more about PBRNs, including what value they bring and how best to work with them. For its part, the PBRN leadership wants to demonstrate value and to become a vital part of the academic research community. In some cases the linkages between CTSAs and PBRNs are strong with respectful communication and a growing capacity to extend research in the community. In other cases, the paths of CTSAs and PBRNs seem not be crossing.

Responses from PBRN Directors and many CTSA Community Engagement Directors support the PBRNs' role as an important and sustainable model to link communities to academia. The practitioners and staff in PBRN practices are community members, with values and approaches to care reflecting community standards.[29–31] Though based in clinical practices, their close community ties give PBRNs a potentially important role in fostering Community-Based Participatory Research.[32,33] Given these structures and functions of PBRNS, CTSAs stand to benefit from working with PBRNs as one important form of community engagement.

It is increasingly important for academic health centers to reach beyond clinic walls and to develop collaboration and expertise in population-based medicine. Optimizing the delivery of preventive health services and chronic illness care requires strong community linkages and will benefit from academic partnerships. To establish the needed relationships for translating research into the community through clinical practice, PBRNs and CTSAs should continue working together to understand and serve different cultures. Advancing these collaborations will require recognizing the complementary nature of `top down'(university-initiated) and `bottom-up' (community-initiated) approaches to community-based-clinical

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research.[34] Continued dialogue and sharing of CTSA/PBRN “best practices” may help reduce missed opportunities and facilitate improvements in population health. We hope our findings will help new and emerging programs to anticipate needs for fostering these ties and help to create realistic expectations by both parties. Ultimately, these CTSA/PBRN partnerships may be perfectly poised to help those academic health centers whose goals include developing stronger ties with the communities in which they are embedded.

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