

EXPERIENCE REPORT

Engaging patients, clinicians, and the community in a Clinical Data Research Network: Lessons learned from the CAPriCORN CDRN

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Funding information

Patient-Centered Outcomes Research Institute, Grant/Award Number: PCORI/CDRN-1306-04737 Phase II

Abstract

Engaging patients, clinicians, and community members in the development of a research network creates opportunities and challenges beyond engagement in discrete learning activities. This paper describes our experiences establishing and maintaining a stakeholder engagement infrastructure for the Chicago Area Patient-Centered Outcomes Research Network (CAPriCORN) and highlights important lessons learned over the first 4 years. During this time, the CAPriCORN Patient and Community Advisory Committee (PCAC) appointed patient, clinician, and community representatives to governance and advisory groups throughout the network, developed a process and criteria for patient- and clinician-centered review of research proposals, and evolved from a large, diverse group to a smaller yet still diverse, more actively engaged group with connections to the broader community. Key challenges faced by the PCAC have included determining the optimal size and composition of the group, understanding the complex structure of the network as a whole, coordinating with other network entities and functions, and integrating the patient and community voice into the research review process. Efforts to engage stakeholders in clinical data research networks should anticipate and develop solutions to address these challenges.

KEYWORDS

clinical data research network, community engagement, patient-centered outcomes research, stakeholder engagement

1 | INTRODUCTION

The ability to harness data from electronic health records has greatly enhanced the national capacity to conduct comparative effectiveness research (CER) in the context of healthcare delivery.¹ Building on this capacity, the Patient-Centered Outcomes Research Institute (PCORI) launched the National Patient-Centered Clinical Research Network

(PCORnet) in 2014 with the goal of enabling CER and patient-centered outcomes research (PCOR) that is faster, easier, less costly, and more relevant to the needs of patients and other decision-makers.²

The engagement of patients, clinicians, and other stakeholders throughout the research process is a defining feature of CER and PCOR. With the growing trend toward stakeholder-engaged research both in the United States and internationally, a significant body of

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literature has emerged surrounding the potential of stakeholder engagement to improve the relevance and impact of clinical research. Although evidence to support one method of engagement over another is currently lacking,³⁻⁵ efforts to delineate the characteristics of successful engagement strategies commonly cite factors such as adequate orientation, clearly defined roles, a concerted effort to establish relationships across perceived hierarchies, and the critical need to build trust early in the research process.⁶⁻⁸

Much of the literature to date has focused on stakeholder engagement in specific tasks such as the development of research agendas⁹⁻¹³ or on the involvement of patients and other stakeholders across the phases of discreet CER and PCOR studies.¹⁴⁻¹⁷ However, effectively engaging stakeholders in the development and oversight of research infrastructure, as required for PCORnet, brings both distinct challenges and corresponding opportunities. In this paper, we describe the process of establishing a Patient and Community Advisory Committee (PCAC) for the Chicago Area Patient-Centered Outcomes Research Network (CAPriCORN) and discuss lessons learned during the initial phase of network development.

CAPriCORN is one of 13 Clinical Data Research Networks (CDRNs) that comprise PCORnet, along with 20 Patient-Powered Research Networks (PPRNs) and two Health Plan Research Networks (HPRNs). CDRNs are collaborations between multiple healthcare delivery systems and rely on the electronic health records of large populations of patients receiving care at participating institutions. The objective of each network is to build the overall capacity of partnering institutions to participate in multinet network randomized trials and observational studies. This requires the creation of complex informatics systems and governance structures, as well as policies and procedures that ensure strict adherence to standards of data security, patient privacy, and research ethics. Although PCORI required that networks applying to participate in PCORnet demonstrate a robust plan for engaging patients and other stakeholders consistent with the PCORI engagement rubric,¹⁸ they intentionally avoided proscribing specific engagement methods, thus allowing each network to design an engagement strategy to fit their unique characteristics and needs.

CDRNs have employed a range of frameworks and methods to engage patients and other healthcare stakeholders (e.g., clinicians and health system leaders) in network-level governance as well as study-specific activities. Some CDRNs built on engagement infrastructures that already existed as part of Clinical and Translational Science Awards^{19,20} or practice-based research networks,²¹ while others, including CAPriCORN, established engagement structures from the ground up. Most networks incorporated multiple levels of engagement, ranging from limited, short-term involvement in specific activities to in-depth, sustained involvement in network governance.²² Methods of engagement include high-touch approaches such as in-person advisory group meetings and listening sessions^{23,24} along with low-touch methods such as online surveys and stakeholder panels.^{20,25} Over the past 4 years, PCORI collected data to describe and assess engagement strategies across PCORnet.²⁶ However, an in-depth, comprehensive evaluation of the effectiveness and impact of specific network engagement strategies has not been undertaken. Reports such as this one that describe the experiences of individual networks can contribute to our understanding of the range of approaches to stakeholder engagement

in research networks, frequently encountered challenges, and the characteristics of successful network engagement strategies.

Initially coordinated by the Chicago Community Trust (and now by Northwestern University), CAPriCORN began as a collaboration among 11 diverse public/private healthcare institutions in the Chicago area, including a county health system, five academic medical centers, a consortium of Federally Qualified Health Centers, and two Veterans' Affairs hospitals. CAPriCORN institutions provide healthcare to over one million patients mirroring the socioeconomic and racial diversity of the region.²⁷

The central governance body for CAPriCORN is a steering committee consisting of representatives from each of the partnering institutions along with one patient and one clinician representative. Working groups advise the steering committee on critical topics including ethics and regulatory issues, informatics, external data requests, health systems leadership, and patient and consumer engagement. The PCAC is the primary forum for patient and stakeholder engagement in CAPriCORN.

The CAPriCORN engagement team drew on the fields of Community-Based Participatory Research (CBPR) and stakeholder engagement in CER to develop a plan for meaningfully engaging key stakeholders in CDRN formation and governance. CBPR and the related field of Community Engaged Research (CEnR), seeks to build authentic partnerships between community members and academic researchers to address issues of greatest concern to the community.^{28,29} CBPR and CEnR take a comprehensive view of health with the goal of reducing health inequities and promote community participation as a means of increasing the relevance and impact of research. Similarly, proponents of stakeholder engagement in CER emphasize that research will be more relevant and useful if patients, clinicians, and other healthcare decision makers are involved throughout the research process.^{17,30} CER differs from CBPR/CEnR in that it focuses on the evidence needs of patients and healthcare professionals and compares two or more health interventions to determine what works best for which patients. Whereas CBPR/CEnR encompasses quantitative and qualitative approaches, CER evidence is primarily quantitative and often relies on sophisticated analytic techniques.³¹

The mission of CAPriCORN, as stated on the website (capricorncdrn.org), is to

"... develop, test, and implement policies and programs that will improve health care quality, health outcomes, and health equity for the richly diverse populations of the metropolitan Chicago region and beyond."

With its emphasis on improving health equity and meeting the health care needs of the Chicago community, CAPriCORN's mission aligns closely with the goals of CBPR/CEnR. However, the complex data infrastructure and initial focus on specific disease cohorts are more characteristic of CER. As described in more detail below, this blending of research disciplines has had important implications for stakeholder engagement in network development and research activities.

As CAPriCORN neared the conclusion of the initial 18-month funding period, we conducted a mixed-method formative evaluation of stakeholder engagement in the network. The results of the evaluation led to a number of immediate changes and also prompted an

ongoing discussion about the most effective and sustainable model of engagement as the network continues to mature. The remainder of this paper will describe the PCAC's formation, initial goals, formative evaluation, adaptations, and future directions.

2 | ESTABLISHING THE PCAC

2.1 | Recruitment and group composition

Determining the optimal composition of the PCAC was complicated by the wide range of institutions, disease areas, neighborhood geography, and stakeholder groups encompassed within CAPriCORN. We sought to include as many perspectives as practical while maintaining a group size that could function effectively. One early decision was to include both clinicians and patient representatives in the same group to facilitate transparency and colearning.

As part of the proposal process, all CDRNs were required to identify rare and common conditions of focus and collect longitudinal cohort data for each. On the basis of areas of local interest and expertise, CAPriCORN identified the following disease cohorts: anemia, asthma, *Clostridium difficile*, weight management/diabetes, and sickle cell disease. Given that patient partners in PCOR projects typically include individuals and organizations that are representative of the population of interest, the PCAC was designed to include patients and clinicians representing the full range of target disease areas for CAPriCORN. We also considered the diversity of the group with regard to gender, race/ethnicity, and age. PCAC members were required to meet at least one of the following qualifications:

- Individuals who have had a personal experience with one of the six priority health conditions
- Health professionals that provide direct patient care to individuals that are affected by one or more of the six priority health conditions
- Community members interested in advocating the patient perspective in health care research
- Health professionals interested in community engaged research
- Representatives from disease-specific patient advocacy/voluntary health organizations

Each institution represented in CAPriCORN was asked to identify potential PCAC participants. Interested individuals submitted a brief application; no one who applied was refused participation. The resulting group included 12 clinicians and 11 patient and community advocates. Clinician members included physicians as well as other care providers (nurse, psychologist, respiratory therapist) from a broad range of Chicago healthcare organizations, including several safety net institutions. Patient advocates included individuals with personal experience related to *Clostridium difficile*, weight management/diabetes, sickle cell disease, and asthma as well as representatives from relevant patient advocacy organizations. The group also included several community advocates without a specific disease focus, including a PCOR advocate/PCORI ambassador, a community

health charities director, a regional health officer for the Illinois Department of Public Health, and a retired pastor with a long history of community advocacy. Sixty-five percent of PCAC members were female. The group included one Hispanic member and was otherwise evenly split between white and black participants. We did not ask members their age, but all were over the age of 30 with the majority in the 40-60 age range.

2.2 | Compensation

All members of the PCAC were provided the same level of compensation for participating in quarterly meetings and were reimbursed for expenses related to meeting attendance (ie, transportation and parking). Members who took on network roles beyond the PCAC received additional compensation.

2.3 | Member orientation

A number of steps were taken to orient PCAC members to CAPriCORN and the role of the PCAC. First, a webinar was conducted to introduce members to PCORI, CAPriCORN, the PCAC, and the importance of stakeholder engagement in PCOR. A PCAC operations manual was provided following the first in-person meeting that included more detailed information. The first few in-person meetings included information and discussion pertaining to PCAC structure and functions, other components of CAPriCORN (eg, informatics and ethics and regulatory working groups), and PCORnet more broadly. These meetings also provided an opportunity for PCAC members to get to know each other as individuals. Given the inclusion of patients and clinicians in the same group, we were cognizant of the potential for perceived power differentials to interfere with group dynamics. Therefore, we introduced procedures aimed at counteracting this tendency such as referring to all members by their first name, engaging clinician/patient dyads in one-on-one conversations, and ensuring that everyone had an equal opportunity to contribute to group discussions.

2.4 | Roles and functions

The PCAC was envisioned as the central hub of patient and clinician engagement within CAPriCORN. In addition to working as a group to develop policies and address challenges as the CDRN developed, PCAC members would be designated to serve as members of the CAPriCORN steering committee, join standing working groups, and participate in ad hoc committees related to specific research projects or issues. Importantly, PCAC members were also intended to serve as liaisons to the broader stakeholder communities they represent, facilitating the transfer of information from and back to the larger community. To facilitate patient and clinician participation throughout the research process, core functions of the PCAC included research prioritization, protocol review, and dissemination of study results.

3 | FORMATIVE EVALUATION

One year following the establishment of the PCAC, we undertook an evaluation to assess progress toward engaging members in network activities, adherence to principles of engagement, and areas for improvement. We used a mixed methods approach that included an online survey of PCAC members and one-on-one interviews with a subset of PCAC members as well as members of the CAPriCORN team.

Responses to the online survey were collected anonymously to encourage members to provide candid feedback. A series of multiple choice questions assessed respondents' perceptions of the PCAC and their role as a PCAC member to date. These included questions related to members' understanding of the goals of CAPriCORN and the role of the PCAC, the size and composition of the PCAC, meeting frequency, duration, and format, the frequency of communication from PCAC staff and the quantity and usefulness of information provided, perceived level of influence, adherence to accepted principles of stakeholder engagement, and topics for future training. Open-ended feedback was also encouraged. Thirty-minute telephone interviews followed a semistructured interview guide and allowed for more in-depth feedback from members of the PCAC. Telephone interviews were also conducted with 10 members of the CAPriCORN project team, including members of the steering committee, work group leads, and members of the Patient and Consumer Engagement Work Group.

There were 24 members of the PCAC at the time of the evaluation. Seventeen completed the online survey for a response rate of 71%. Of these, six self identified as "patient representatives," six as "community representatives," and five as "clinicians." The response rate for patient/community representatives combined was 100% versus 42% for clinicians. Three patient/community representatives and five clinicians participated in follow-up interviews.

Frequency distributions for each item in the online survey were calculated separately for patient/community representatives and clinicians. Survey and interview data were analyzed with the goal of identifying ways to strengthen the PCAC as a group and optimize its role within CAPriCORN. The following lessons learned are based on the results of the evaluation combined with our ongoing experience working with the PCAC to address the evolving needs of the CDRN.

4 | LESSONS LEARNED

Chief among the PCAC's accomplishments over the past 4 years has been bringing together a richly diverse group of stakeholders with the shared goal of leveraging CAPriCORN's potential to improve the health of Chicago patients and communities. In addition to the valuable insights, they have already provided, it is our hope that all members of the PCAC will carry forward a sense of empowerment to engage as active partners in research rather than passive participants. Two perspectives on the personal benefits of participation in the PCAC are expressed in the following:

"As a cancer survivor, I was able to learn from individuals who translated their own health care journey into advocacy."

"Being a member of the of the PCAC has given me the opportunity not only to build and foster new relationships, but has also enhanced my understanding of the role and value of research in identifying and developing novel approaches for the management of chronic conditions."

From the PCAC's inception, we engaged in an ongoing process of shaping the group's focus and functions to meet the needs of a complex and ever-evolving CDRN. We immediately encountered challenges related to the appropriate composition of the group, followed by a number of challenges related to the role and functions of the PCAC within the broader CAPriCORN network. The experiences and insights gained along the way may be informative for others seeking to ensure that healthcare systems engaged in continuous research and learning activities maintain a primary focus on the needs of patients and the clinicians who care for them.

4.1 | Complexity of network development

Although perhaps overused, the metaphor of "building a plane while flying it" aptly describes the experience of launching a group intended to advise a structure that does not yet exist and defies all attempts at simple explanation. Nonetheless, waiting until CAPriCORN was up and running to bring in patient and clinician perspectives was neither possible nor advisable. The extensive work that went into developing the PCORI funding application produced a detailed blueprint of what the network would look like and what it could accomplish. However, moving from a plan on paper to an operable network is a long and arduous process.

Every effort was made during the PCAC orientation process to build a foundation of understanding about the overall structure and goals of CAPriCORN. However, fully grasping the complex and evolving network structure and understanding the role of the PCAC was a difficult task, even for more experienced participants. As described by one patient representative

"The biggest challenge was overcoming the knowledge gap. I didn't have training and couldn't understand everything that was being discussed."

This was compounded by the long time span between quarterly PCAC meetings. Not surprisingly, in an online survey of PCAC members 1 year after the group was first convened, 35% of respondents indicated that they had only a basic understanding of CAPriCORN and would have difficulty describing the network goals. Moreover, 59% of respondents reported only a basic understanding of the role of the PCAC within CAPriCORN. During subsequent one-on-one phone interviews, some members clarified that while they understood the goals of the PCAC, it was not clear how those goals would be accomplished.

These findings highlighted the need to continuously reiterate and clarify what the CDRN and the PCAC were seeking to accomplish. To increase member awareness of network goals and activities, a newsletter was developed for distribution between quarterly meetings,

and each PCAC meeting began opening with an update on network activities.

A related challenge involved maintaining group members' interest and commitment when the timeline for seeing tangible benefits may extend far into the future. Actively engaging stakeholders over the course of a multiyear research study is itself a difficult task. The challenge is compounded when a significant time period is required for the network to become "research ready." Finding ways to demonstrate that progress is being made and help stakeholders remain committed to the ultimate network goals is critical to sustaining engagement.

4.2 | PCAC breadth versus depth

The size and composition of the PCAC created additional challenges. The group was initially constructed to include as many patient and clinician perspectives as possible. The benefit of this approach was the diverse range of perspectives and areas of interest represented on the PCAC. In the 1-year evaluation, the vast majority of respondents felt that the size of the group was appropriate (N = 24 at the time of the survey), and several members pointed out patient perspectives that were missing and should be added to the group.

Although the breadth of membership in the PCAC was viewed by most as a positive, it also restricted the ability to engage individual members at greater depth and frequency. Some members expressed a desire to be more actively involved in network activities, and as a result, PCAC leadership initiated a process to match interested PCAC members to a variety of roles within the broader network. In addition to appointing one patient/community representative and one clinician to the steering committee, PCAC members joined the executive committee (responsible for coordinating the activities of the steering committee), the Chicago Area Institutional Review Board (CHAIRb), the communications committee, the Clinical Research Working Group, and several disease cohort working groups (asthma, sickle cell disease, and weight management). The experiences of PCAC members in these different roles were mixed. Whereas some members were well integrated into the existing groups and able to make meaningful contributions, others did not feel that they were provided the training and support needed to participate fully. PCAC members indicated that the location and timing of meetings and sometimes inadequate notice of upcoming meetings, were barriers to participation.

4.3 | Research process and timelines

Other challenges were associated with the process for integrating PCAC input into research initiated or supported by CAPriCORN. A critical early task for the network was determining how requests to use CAPriCORN data, or otherwise collaborate with the CDRN, would be vetted and approved by the appropriate groups and committees. PCAC initiated a process flow diagram to show how community voices could be integrated into the research process and to help visualize the CAPriCORN/PCORnet imperative of maintaining patient centeredness while respecting the overall goal of creating infrastructure and processes to facilitate research. The resulting plan required that PCAC review any request that involved identifiable patient data or contact

with CAPriCORN patients or clinicians. In addition, the PCAC would only be asked to review requests for which a full proposal or study protocol was available (ie, requests for preliminary, nonbinding letters of support were not reviewed by the PCAC).

With the role of the PCAC in the overall review and approval process defined, the group set out to determine the process and criteria that would be used for PCAC reviews. Patient and stakeholder partners in individual research studies typically have direct experience with the disease or condition in question and are therefore able to provide very specific input regarding appropriate research questions, procedures, and outcomes. Because the PCAC would need to consider research related to any given disease area, the review criteria needed to be broadly applicable and not require experience or expertise relevant to a specific condition.

During an early in-person meeting, the PCAC developed a list of study outcome domains that they considered high priority. These included outcomes that, although important to members of the PCAC, are not typically included in research protocols. For example, the group felt strongly that outcomes related to caregiver burden should be more frequently considered. The resulting list of desirable outcome domains became one component of the PCAC review criteria. Although requests were not discounted for failure to include certain outcomes, feedback to investigators included suggestions for relevant outcomes that could strengthen the patient-centeredness of their research. The full set of review criteria is included in Table 1.

With regard to the process for PCAC reviews, it was critical to consider the rapid timelines often associated with research-related requests. A small group of PCAC members convened to finalize the review criteria and forms, test them out by reviewing several protocols as a group, and develop a plan for training additional PCAC members to serve as reviewers. Despite this preparation, it has proven difficult to integrate PCAC review into the overall network review and approval process. A clinician representative on the PCAC described it this way

"The workflow did not permit PCAC to provide researchers with feedback on their study design early enough in the process. As a result, the potential benefit to the community and researchers was not fully realized."

This has been partly because of the lack of a robust pipeline of proposals requiring PCAC review and therefore a lack of training opportunities, as the CDRN worked toward becoming fully operational. The variety of ways in which requests were coming into the network also contributed to the challenge. The recent opening of CAPriCORN's "Front Door" (a centralized portal for all research-related requests) should lead to an increased proposal pipeline and also help to streamline the overall process, including review by the PCAC when required.

5 | FUTURE DIRECTION

As the conclusion of the PCOR1 funding period approaches, and CAPriCORN looks toward a streamlined and sustainable path forward, the PCAC leadership team closely examined the lessons learned about

TABLE 1 Patient and Community Advisory Committee (PCAC) proposal review criteria

| Criterion | Subcriteria |
|---|---|
| Criterion 1: Is the proposed research focused on questions and outcomes of specific interest to patients, their caregivers, and clinicians? | (a) Is the proposed research question likely to be of interest to patients, their caregivers, and clinicians? (b) Are outcomes included that will be of interest to patients, their caregivers, and clinicians? |
| Criterion 2: Are there adequate procedures for recruitment, informed consent, and feedback to participants? | (a) Does the recruitment strategy include approaches likely to be successful with the population(s) of interest? (b) Do plans for obtaining informed consent minimize burden to participants while maximizing their ability to make truly informed decisions? (c) Will participants be appropriately compensated for their time, effort, and expenses? (d) Is there a plan for following up with participants once the study is completed? |
| Criterion 3: Are there adequate plans for preserving privacy and confidentiality? | (a) Are you satisfied that the proposal pays sufficient attention to issues of privacy and confidentiality? |
| Criterion 4: Are issues related to the flow of clinical care adequately addressed? | (a) Is the role of clinical staff in recruitment, informed consent, and data collection clearly described? (b) Does the study protocol minimize burden to clinicians and patients? (c) Does the study protocol preserve the primacy of the doctor-patient relationship? |
| Criterion 5: Is there a reasonable plan for engaging patients and other stakeholders throughout the proposed research? | (a) Were patients and other stakeholders involved in planning the study? (b) Will patients and other stakeholders participate in study conduct? (c) Will patients and other stakeholders be involved in plans to disseminate study findings? |

patient and clinician engagement in CAPriCORN along with the evolving needs of the network. With input from the PCAC membership, a plan was developed that seeks to ensure that the network maintains its focus on the needs of patients and the community, while maximizing the use of available resources.

The transition was marked by changing the name of the group from the patient and clinician advisory committee to the patient and community advisory committee. This was not intended to minimize the importance of clinician views but rather to elevate and empower patient and community leadership of the group. The group will maintain a balance of two patient/community representatives to everyone health professional, with a total group size of eight to ten individuals. Whereas the PCAC was previously cochaired by clinicians from two participating institutions with expertise in community engagement, the group is now led by two community representatives with support from patient and clinician mentors. A patient representative on the PCAC described the transition this way:

"Most notable to me is the rising up, and assertion, of leadership among the non-clinician members. I am inspired by the commitment, vision, and determination of our new co-chairs, bringing a heightened sense of purpose, duty, and opportunity to the group."

Rather than including individuals with interests specific to particular disease areas, the PCAC is now composed of community members and health professionals interested in advocating for the patient perspective in health care research. An emphasis was placed on including individuals who can serve as liaisons to the broader stakeholder communities they represent. In this respect, the current composition is more aligned with frameworks for community engagement as opposed to patient engagement.²¹ Membership now includes representatives from the Illinois Human Rights Commission, Leadership Greater Chicago, the Alliance for Research in the Chicagoland Community, the Sickle Cell Disease Association of Illinois and the Sickle Cell Action Network, Jesse Brown VA Medical Center, Howard Brown Health Center, the University of Chicago (community relations), and the University of Illinois at Chicago. In addition to serving on the PCAC, each member of the newly formed group was asked to participate in a network committee or working group.

All original PCAC members were invited to volunteer for participation in the smaller, more actively engaged group. Those who declined participation but indicated interest in remaining involved on an ad hoc basis will be retained on a contact list that includes their particular areas of interest or expertise. These individuals will be queried as opportunities relevant to their areas of interest emerge (eg, to provide input on research proposals).

The resulting model of engagement accommodates differing levels of interest and availability among stakeholders, including: (1) a small number of highly motivated PCAC members who are responsible for ensuring that the patient and community voice is heard throughout the network, (2) a somewhat larger group who provide ongoing guidance to PCAC leadership and serve as liaisons to the communities they represent, and (3) an expanded list of patient and community members who are interested in contributing to CAPriCORN in more specific, short-term activities. A similar multilevel model of stakeholder engagement has been employed by the Mid-South CDRN.²⁰

As this new engagement model has only recently been implemented, it is too soon to assess its effectiveness and determine whether it improves upon the original model. Ongoing evaluation that examines the impact of engagement on network outcomes, adherence to established principles of engagement, and stakeholder satisfaction is critical.

6 | CONCLUSIONS

The experiences of the CAPriCORN PCAC to date highlight some key challenges and potential solutions that may be informative for others attempting to engage patients and other stakeholders in creating a sustainable, patient-centered research network. First, network formation is a complex and dynamic process, and stakeholders may struggle

to grasp and maintain commitment to potential outcomes that may take years to fully materialize. Multiple strategies are needed to convey the ultimate goal of improving health outcomes and to demonstrate progress toward that goal. Second, it can be challenging to determine the appropriate advisory group composition for a broadly focused, multisystem network such as CAPriCORN. A large, diverse group offered some early advantages in terms of representation of multiple viewpoints. However, we found that a smaller, more actively engaged group with connections to the broader community made more sense once the network was fully functional. Whether for a multisystem network or a single institution, careful consideration should be given to the role and responsibilities of the advisory group and the population it is intended to represent. Finally, incorporating patient and community input into the research review process can be complicated by short timelines, requests from diverse sources, and multiple levels of review and approval. Involving all network stakeholders in developing a review process that recognizes the importance of the patient/community perspective and enables meaningful participation is critical.

ACKNOWLEDGEMENTS

The authors wish to thank all current and past members of the CAPriCORN PCAC for their valuable contributions. This work was funded by the Patient-Centered Outcomes Research Institute.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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How to cite this article: Tambor E, Shalowitz M, Harrington JM, et al. Engaging patients, clinicians, and the community in a Clinical Data Research Network: Lessons learned from the CAPriCORN CDRN. *Learn Health Sys*. 2019;3:e10079. <https://doi.org/10.1002/lrh2.10079>