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Patient Governance in a Patient-Powered Research Network for Adult Rheumatologic Conditions

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Background: Patient-Powered Research Networks (PPRNs) are a unique type of patient-powered patient registry for patient-centered outcomes research requiring that stakeholder engagement play a key role in governance (eg, research guidance and decision making). The purpose of this report is to describe the governance structure of a newly formed PPRN and the activities undertaken prelaunch and postlaunch to evaluate and improve the engagement of patient stakeholders in governance.

Methods: During the 18-month start-up period of ArthritisPower, a PPRN for adult rheumatologic conditions, 12 members of the patient body of the PPRN governance completed a 12-item preassessment and postassessment based on the Patient-Centered Outcomes Research Institute (PCORI) Engagement Rubric. The assessment was intended to measure Patient Governor (PG) perceptions of their engagement in governance within the first 3 months of their involvement at an in-person orientation. Six months later, the PG Chair initiated a mid-year evaluation with the same group to identify areas for improvement. Semistructured phone interviews were conducted with 11 PGs who were asked to rate and explain their perceptions about their participation in PPRN governance, the progress of the PPRN toward conducting research, the support they receive from staff, and the support they receive from other PGs. Results were compiled and interpreted by the Chair with help from the coprincipal investigator.

Results: Preassessment/postassessments indicated that PGs understood their governance role and decision-making authority after in-person

orientation and felt that major PPRN decisions were being made with their input. Feedback and scores from the PG-led mid-year evaluation coalesced around 3 themes: a preference for receiving news and updates via email to allow more discussion and decision making during conference calls, a desire for guidance about how best to help advance the PPRN toward the conduct of research, and a need to communicate with each other as a group outside of monthly conference calls. Suggested activities to support patient engagement in PPRN governance include communicating clear expectations, providing well-prepared tools for engagement, and conducting regular assessments.

Conclusions: Members of an online patient community are willing to share their expertise to participate in and shape research governance and bring both their professional and lived health experience to the development and improvement of PPRN governance structure. A patient-initiated and patient-led evaluation of governance communication procedures within the PPRN provided more specific recommendations for improvement than did an investigator-led preevaluation/postevaluation based on the PCORI Engagement Rubric.

Key Words: research governance, Patient-Powered Research Network (PPRN), patient-centered outcomes research (PCOR), stakeholder engagement, arthritis/rheumatology

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Patient-Powered Research Networks (PPRNs) are a unique type of patient registry whose purpose suggests a governance structure that models effective stakeholder engagement. The purpose of this report is to describe the governance structure of a PPRN during the 18-month start-up period and the activities undertaken prelaunch and postlaunch to evaluate and improve the engagement of patient stakeholders in PPRN governance.

A patient registry is a collection of detailed, standardized information about patients with a specific condition or experience.[1] Sometimes referred to as clinical registries, disease registries, or outcomes registries, they are managed by a clinical/academic institution or patient organization that uses observational study methods to gather data and study health outcomes of the patient population.[2] PPRNs are a subtype of patient registry that are "powered" by patients and/or family members who inform the research agenda, control, or manage data collection and analysis, and guide dissemination and translation of findings.[2] Like other patient-powered patient registries, PPRNs are usually run by a patient advocacy organization. However, PPRNs are distinct from patient-powered patient registries in 2 ways: (1) a patient serves as principal investigator or coprincipal investigator (co-PI)[3]; and (2) the PPRN participates in a broader research

collaborative with shared infrastructure and standardized data collection across multiple registries for 1 or many conditions.[2] In short, PPRNs conduct studies led by patients either within their own registry or in collaboration with peer registries in a distributed research network (DRN).

Setting up governing bodies that include stakeholders is strongly recommended by the Patient-Centered Outcomes Research Institute (PCORI) for both PPRNs and DRNs.[3,4] Governance, "the system of administration and supervision through which research is managed, participants and staff are protected, and accountability is assured,"[5] can follow different models: from a single steering committee to multiple bodies.[1] The role of governance bodies varies across and within registries and includes: steering major financial, administrative, legal, ethical, and scientific decisions; determining who has access to data and the process for requesting data for analysis; developing and maintaining relationships with research partners, funding sources, registry participants and other stakeholders;[1] and ensuring that research is conducted for the benefit of registry stakeholders.[6] Implementing a governance structure that advances core principles of stakeholder engagement is especially appropriate in comparative effectiveness research (CER) and patient-centered outcomes research (PCOR) where evidence generation and dissemination explicitly focus on addressing the decision-making needs of patients, clinicians, and other stakeholders.[7,8]

Stakeholder engagement is "informed decision making about the prioritization, conduct, and use of research" among those individuals or groups responsible for or affected by health-related and health care–related decisions that can be informed by evidence.[9,10] The PCORI Engagement Rubric describes 6 principles of stakeholder engagement: reciprocal relationships, colearning, partnerships, transparency, honesty, and trust.[11] The unique characteristics of PPRNs, coupled with a mission to advance PCOR and CER in specific conditions, logically call for incorporation of these principles into governance structure and processes.

In 2014, PCORI invested in the development of the National Patient-Centered Clinical Research Network (PCORnet), a DRN, and collaborative of PPRNs and Clinical Data Research Networks to conduct CER.[12] ArthritisPower, the public name of ARthritis Patient Partnership with Comparative Effectiveness Researchers (AR-PoWER) PPRN, is 1 of 20 PPRNs in PCORnet. It is a partnership of the Creaky-Joints (CJ) arthritis patient community and researchers at the University of Alabama at Birmingham and the Global Healthy Living Foundation, a patient advocacy organization. Before launching, ArthritisPower established a governance structure that included an Executive Board, Patient Governor Group (PGG), and Research Advisory Board (Fig. 1). The governance structure was developed collaboratively by co-PIs of ArthritisPower and CJ members. People living with rheumatologic conditions (patients) are represented on 3 of 4 bodies within the governance structure: a patient PI chairs the Executive Board; the PGG is a patient steering committee composed of 10–12 patients from a variety of professional, geographic, and demographic backgrounds intended to represent the diversity of the patient community in terms of age, sex, race/ethnicity, and health condition; and the Research Advisory Board is composed of the PGG patient chair, researchers (including rheumatologists), other physicians, and industry representatives.

Although research governance is not new, little has been reported about PPRN governance structure and activities and their connection to stakeholder engagement. This report describes the development and implementation of the patient component of the governance structure of a newly launched PPRN for adult rheumatologic conditions, and its use of PCORI Engagement Principles[11] to inform and improve governance processes.

METHODS

Development of the PGG, Patient Leadership Committee of PPRN Governance Structure

As displayed in Figure 2, the governance structure was conceived during the months leading up to PPRN launch (ie, when patients started consenting to participate in ArthritisPower via online portal or mobile app equivalent). Once the PPRN co-PIs had outlined a governance structure, 6 highly engaged patients (bloggers, health activists) helped co-PIs define the Patient Governor (PG) role. It was agreed among co-PIs and patient advisors that one of the governance bodies in the structure should be made up entirely of patients to strengthen the voice of the patient within the PPRN and because patients would have different training needs than other members of the governance whose professional work entails constant exposure to research concepts. Establishing patient representation and overlapping membership on all 3 boards was considered to be important for transparency and trust, particularly among patient stakeholders. A PGG
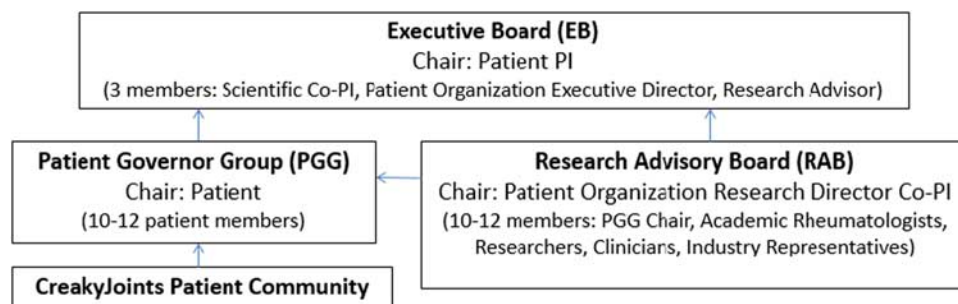

FIGURE 1. ArthritisPower PPRN Governance Structure. Co-PI indicates coprincipal investigator; PI, principal investigator; PPRN, Patient-Powered Research Network.
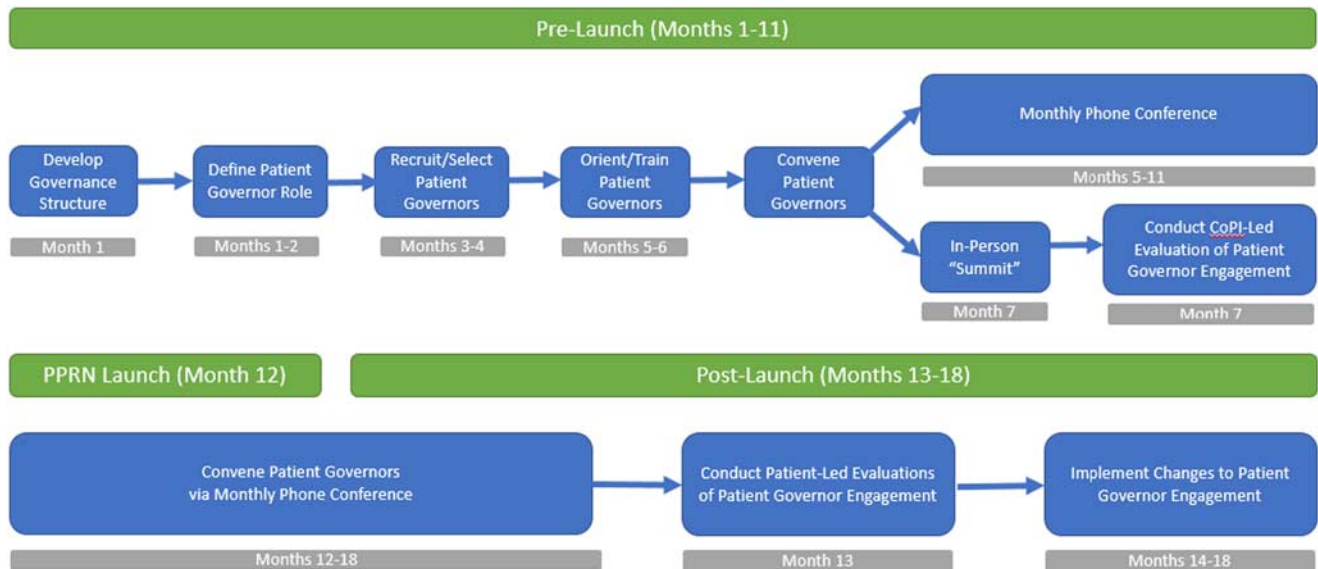
FIGURE 2. Overview of PGG development, engagement, and evaluation during 18-month PPRN start-up period. Co-PI indicates coprincipal investigator; PGG, Patient Governor Group; PPRN, Patient-Powered Research Network.

outreach flyer, position description, and application forms were created and revised with their input. Selection of PGs was criteria-based (Table 1). After being recruited and interviewed by ArthritisPower co-PIs, 12 leaders from the CJ community were identified to serve on a 3-year, rotating membership PGG with a minimum requested time commitment of 2 hours per month on an average. The 2-hour minimum was estimated based on scheduled hour-long monthly conference calls and 1 additional hour for reading emails and reviewing documents.

During the prelaunch period following PG selection, the PGG participated in monthly hour-long conference calls with co-PIs and completed 2 self-directed courses as part of their orientation: (1) the Collaborative Institutional Training Initiative Human Subjects Protection online training to gain an understanding of research ethics; and (2) the Cochrane Collaboration's *Understanding Evidence-Based Healthcare* online modules as evidence-based health care underpins the rationale for PCOR. PGs also attended an in-person "Summit" with the following objectives: understand PG role and PPRN aims, build relationships with other PGs, review basic

TABLE 1. Criteria for Patient Governor Selection

(1) Experience advocating on behalf of rheumatologic conditions or for own diagnosis and/or treatment
(2) Facilitative and collaborative approach to group discussion and decision making
(3) Commitment to fostering representativeness across demographic factors (ie, supportive of the need for the Patient Governor Group and the patient-centric registry to reflect sex, age, race/ethnicity, regional diversity)
(4) Willingness to be a public face of rheumatology research
(5) Existing relationship and involvement with the patient community and advocacy organization (CreakyJoints)
(6) Skills necessary for patient-powered research (eg, outreach/recruitment, public speaking, social media, information technology, research design/ analysis/dissemination)
(7) Dependable, committed, and responsive

research concepts, and reach agreement on governance issues (eg, PGG charter and decision-making processes). At the end of the Summit, a subset of PGG patients who had rheumatoid arthritis participated in a patient panel for clinical practice guidelines.[13]

To assess the engagement of PGs, a preassessment/ postassessment was constructed to be administered to the 12 PGs before and after the Summit. The measure was created by referencing elements of the PCORI Engagement Rubric[11] including the following 6 principles: reciprocal relationships, colearning, partnerships, transparency, honesty, and trust. Each item was mapped to the principles (Appendix, Supplemental Digital Content 1, http://links.lww.com/MLR/B477). An antecedent, the PCORI Patient and Family Engagement Rubric,[14] was also referenced in developing the measure. The assessment was piloted with 5 non-PG members of the patient community and revised based on their feedback. The authors of this report were interested in understanding PGs' perception of the their engagement in PPRN research and examining the extent to which the in-person Summit affected PGs' grasp of their research governance role. Using a Likert scale where 1 = strongly disagree and 6 = strongly agree, PGs were asked to rate items before and after the Summit (Appendix, Supplemental Digital Content 1, http://links.lww.com/MLR/ B477). Following the Summit, a mean rating for each item at pretest and posttest was calculated along with change in average score.

During subsequent months, PGs continued to participate in monthly conference calls focused on research methods, PPRN and PCORnet updates, and discussion of studies proposing to utilize ArthritisPower infrastructure and data (Fig. 2). PGs were asked to provide input and make decisions about ArthritisPower including feedback on the informed consent form and data collection software development that is part of the registry. During such calls, PGs determined initial scope and frequency (eg, once weekly) for the routine data

collection of core patient-reported outcome measures by ArthritisPower participants. Additional examples of PGG activities and decisions are outlined in Table 2. PG assistance in drafting and editing the informed consent form and improving the mobile app was particularly helpful. They suggested that we answer in simple terms the following question within the consent form: how will data in the Registry be stored, extracted, and used? They were confused by a statement about not losing benefits (ie, "if you decide not to be in the Registry, you will not lose any benefits you are otherwise owed") and asked that it be rephrased as, "you won't lose any benefits that you would be receiving regardless of your participation in the Registry." As a result of PGs' feedback, we added sections to the consent form that responded to their concerns and clarified language they found difficult or obscuring. A PG with professional experience in market research initiated an evaluation of user interface/user experience of version 1.0 of the ArthritisPower app that generated data to inform subsequent iterations of the app.

Patient-led Evaluation of Governance Body Processes and Communication

Six months after the Summit and preassessment/postassessment, the patient chair of the PGG initiated a mid-year evaluation of the governance body to examine PGs' feelings about and perceptions of their engagement with ArthritisPower and its governance activities and to identify areas for improvement (Appendix, Supplemental Digital Content 1, http://links.lww.com/MLR/B477). She devised a list of open-ended questions that were shared with the co-PIs, but were not pilot-tested. The Chair conducted semistructured phone interviews with each of the 11 other PGs and noted their

TABLE 2. ArthritisPower Patient Governance Activities During Start-Up

Established the Charter for their group by electing a Chairperson, agreeing on a majority vote decision-making process, and forming subcommittees for participant recruitment and data security

Selected PRO domains (ie, symptoms such as fatigue) to be routinely captured for all ArthritisPower participants

Edited the draft informed consent form to clarify and simplify the informed consent language

Chose a template for the project proposal form (summary research proposal and approval process) to outline how external researchers may propose and conduct analyses using ArthritisPower registry data

Provided consultative input in the development of use case diagrams to differentiate research topics that are patient-initiated from those proposed by PCORnet partners and external researchers

Gave feedback to expand and improve the usability of the ArthritisPower app, including better integration with the CJ website and social media; an emailed report for participants to easily share health-tracking results with their doctor; and more intuitive interpretations of Patient-Reported Outcomes Measurement Information System scores

Conducted a survey to determine preferred ArthritisPower value propositions and recruitment messages

Revised ArthritisPower recruitment messaging to be more patient-friendly

Assisted in the design and implementation of a crowd-sourcing feature, "tell us what you want to know," enabling the CJ patient community to propose and rate topics to be reviewed and prioritized by PGs in the development of a guiding research agenda document

CJ indicates CreakyJoints; PCORnet, National Patient-Centered Clinical Research Network; PG, Patient Governor; PRO, patient-reported outcome.

scores and comments in excel. Interviewees were asked to give a score from 1 (terrible) to 10 (great) and to elaborate their feelings about the registry progress, their governance participation, support they received from staff, and support they gave to other PGs.

Quantitative and qualitative results were compiled and interpreted by the PGG Chair with help from a co-PI. A mean score for each of the four items was calculated. Comments from the interviews were organized by theme to identify actionable recommendations. A summary of results was then shared with ArthritisPower staff and other PGs.

RESULTS

Preassessment/postassessments at the in-person meeting indicated that most PGs agreed with a majority of the items (Appendix, Supplemental Digital Content 1, http://links.lww.com/MLR/B477). From preassessment to postassessment, the largest average changes were observed on items measuring their understanding of their governance role (Q.6, Q.8) and their sense that major decisions about the PPRN were being made with their input (Q.11). The largest increase in agreement was on the item addressing the clarity of the PG role. Other items having to do with general questions about the importance of patient engagement in research (ie, "it is best for research when patient partners participate in and monitor how a study is conducted") or whether PGs' individual needs and differences would be accommodated by PPRN staff changed slightly or not at all. Only 1 item, perception of whether PGs were being compensated fairly, decreased from preassessment to postassessment, though only slightly. Overall, PGs agreed that they understood their governance role and decision-making authority after the Summit and felt that major decisions about ArthritisPower were being made with their input.

Scores from the patient-led mid-year PGG evaluation showed that the highest average score regarded support from staff (8.6), the lowest average score concerned respondents' feelings about their own participation on the governance group (6.6). Concerning PGs' general feeling about the progress of ArthritisPower toward conducting PCOR, and their general feeling of the support received from other PG, each item received an average score of 7.3.

Three themes emerged from comments made during follow-up probes (ie, "what would help improve your engagement with the patient governor group?") in the mid-year interviews. First, PGs preferred using monthly conference calls for discussion and decision making, not updates. One PG remarked, "it would be nice to receive 1 regular document with 'here's how it works,' so we don't spend time on calls updating everyone." Another said, "we should use calls for working, not updating!" Second, PGs felt that they wanted to do more to help with ArthritisPower progress, but were unsure how to help. One PG said, "I don't know what we should be doing or what is coming up." Another expressed similar frustration, saying, "I feel like I could be doing more, but I don't know where to go." In response to feedback from PGs contained in the first 2 themes, ArthritisPower staff instituted several new procedures. Specifically, co-PIs immediately

began sending regular email updates with "action items" to the PGG every 2–6 weeks. Content and attachments from these emails were saved to a master reference file available to all PGs in the event that they could not retrieve an email that had been sent. Co-PIs also realigned subsequent monthly conference call agendas to include only brief, action-oriented updates to allow the bulk of the hour to be spent discussing study proposals with research affiliates or problem-solving issues within the PPRN infrastructure (ie, app development, participant recruitment). The third theme that emerged from the patient-led evaluation was that PGs wanted to be able to communicate with each other as a group outside of monthly conference calls with staff: "Talking with other members helps me feel connected. I wish there were more opportunities to socialize with the PGG." To address this, ArthritisPower staff created a private Facebook group for the PGG were members could ask each other questions and work on governance tasks together. Content from ArthritisPower update emails was also saved to the Facebook group for easy reference when PGs were needed to consult prior PPRN communications and documents.

DISCUSSION AND CONCLUSIONS

During the start-up year of a PPRN for adult rheumatologic conditions, we sought to develop a governance structure with an all-patient governance body, the PGG, based on principles outlined in the PCORI Engagement Rubric.[11] We used both an investigator-led and a patient-led evaluation approach to inform and improve registry governance processes. These evaluations provided insight into the factors that facilitate the development and continuance of a patient governance structure.

Results from the investigator-led evaluation indicated that the in-person orientation Summit with PGs was useful in clarifying patients' understanding of their governance role and fostering a sense of inclusion and transparency in PPRN research activities. The biggest increase between preassessment and postassessment was observed for PG grasp of the role. This was expected given that primary objectives of the Summit included increasing understanding of the PG role and working together to make decisions about governance (ie, edits to PGG Charter). However, there was little or no change for most items on the preassessment/postassessment either because it was too early in the development of the registry for these items to be relevant or because the statements were too vague to meaningfully measure engagement in PPRN governance. Although both the Summit objectives and the preassessment/postassessment were designed with PCORI Engagement Principles[11] in mind, the primary concern of PGs seemed to be gaining a deeper understanding their own role in the governance and not in activating the governance role itself because at that point the PPRN had not yet been launched and no patients had consented to participate. And although both evaluations were instructive, the mid-year patient-led approach was more useful in developing and improving engagement activities in the short term. Specifically, it led to concrete changes in the agenda and facilitation of conference calls and prompted staff to set up a private online

environment for PGs to communicate with each other between monthly calls. The changes that were implemented yielded more effective engagement and satisfaction among PGs as evidenced by their increased participation in discussions during conference calls and the desire of all but 2 PGs to remain part of the PGG for another term. The superior utility of the patient-led assessment was likely due to at least 3 factors. First, it was conducted using qualitative methods which afforded the opportunity to ask follow-up questions and elicit more comprehensive descriptions of PGs' perceptions. Second, it was conducted by a patient peer so PGs perhaps felt comfortable speaking with candor and frankness about their perceptions. Third, the timing of the investigator-led evaluation may have been too early in the process to surface recommended changes to governance procedures and communications with staff. PGs had just completed their orientation and only a 2 months of conference calls had transpired.

Overall, we learned that it is important to create a governance structure that encourages proactivity and fosters PG feeling comfortable about sharing their expertise, talents, and perspectives. Meaningful patient participation in the governance of a research registry is valuable in developing a governance charter and in helping to design study protocols, informed consent documents, recruitment materials, outreach strategies, and dissemination tools. PG participation as partners in research can be supported by the activities outlined in

TABLE 3. Activities to Support Patient Governance of PPRN

Communicating clear expectations
    Provide a PG position description that includes expectations about time commitment and tasks involved
    Ensure PGs understand the scope of what they are being asked to do (and not do) to avoid misunderstandings
    Create opportunities for PGs to ask clarifying questions about their role (eg, during conference calls or in-person meetings)
    Orient and/or train PGs in basic research methods, research ethics, and evidence-based health care (eg, how to ask research questions in a testable way)
    Create opportunities for PGs to practice their role (eg, by presenting a research proposal and asking specific questions about the feasibility of recruiting participants or collecting data)
Partnering with staff
    Orient research staff to PCOR principles and prepare staff to work alongside PGs (eg, flexible communication, expectation of feedback, transparency)
    Introduce PGs to research project staff and encourage staff to engage with PGs
Providing tools for engagement
    Seek out diverse opinions (eg, select diverse group of PGs, follow-up with "quieter" PGs)
    Offer multiple options for PGs to communicate and interact with other PGs and project staff (eg, in-person meeting, email, online platform like private Facebook group)
    Establish work groups (short term/long term) organized around particular topics or tasks where more work is needed (eg, to assist in the development of PRO data collection tools)
Conducting regular assessments
    Ask PGs for feedback both quantitatively (surveys) and qualitatively (interviews)
    Compile and share results with PGs and staff for discussion

PCOR indicates patient-centered outcomes research; PG, Patient Governor; PPRN, Patient-Powered Research Network; PRO, patient-reported outcome.

Table 3. We learned through this process that it is important to conduct regular assessments of stakeholder engagement among members of patients within the governance structure, particularly assessments that encourage members to share their suggestions about improvements that could be made. This approach is consistent with advancing PCORI Engagement Principles,[11] notably principles of reciprocal relationship, colearning, honesty, and trust.

We also identified several potential challenges. As patients who engage as PGs become more trained and practiced in research methods, they risk becoming less representative of the general patient constituency. To mitigate this risk, the governance charter requires PGs to cycle off within 3 years to maintain a mix of veteran and new members. Sometimes it is also necessary to reach out to a broader group of people to make decisions rather than just a dozen PGs. We developed a larger group called Patient Partners in Research to expand the pool of people who are ready to provide input. There is a constant tension in any governing body that purports to be representative between having a small enough group to make decisions for the whole and having a large and diverse enough group to represent all-patient voices in the deliberations. One way we have sought to do this is by targeted recruitment of new PGs to incorporate perspectives (ie, diverse disease, cultural, or sociodemographic characteristics) that may otherwise be overlooked that are brought to our attention by members of the patient community and other stakeholders. For example, 1 patient in the Patient Partners in Research group was concerned that we were not conducting studies specifically on spondyloarthritis. As a result, we actively sought new members with the condition.

This report of governance activities and data about PG perceptions of engagement faced an important limitation. First, we did not seek sufficient guidance from experts or prior literature on stakeholder engagement when designing PPRN governance activities and assessments. Our methods and the timing of implementation of evaluations might have been improved with expert guidance. This limitation, however, underscores the lack of evidence to help inform the use of governance structure, and specifically a patient governance body, as a core component of stakeholder engagement. In upcoming PGG terms, we plan to improve our evaluation approaches to more consciously achieve outcomes in alignment with overall PPRN research aims.

In conclusion, we found that clear expectations, well-prepared tools for engagement, and regular assessments are necessary to maximize the contributions of patients within a multistakeholder governance structure to launch and maintain a PPRN/registry. The formation and maintenance of a governance structure that includes multiple governance bodies requires time, preparation, and an openness to making adjustments to respond to the needs of the PPRN and, in particular, to input from community members selected for research stewardship. Staff of patient advocacy and research organizations have a dual responsibility to work with these members, in this case members of the PGG, to support them in participating as activated research partners while building their capacity and expertise to do so.[15] Members of an online patient community like CreakyJoints are willing to participate in and bring valuable expertise to

PCOR governance to shape research network decision making and processes. The patient-initiated and patient-led evaluation described here provides 1 example. Research to generate evidence about those stakeholder engagement approaches that are most effective is needed,[9] and we propose that more research should be conducted to understand the strengths and weaknesses of various governance structures and processes within PPRNs. Future studies comparing engagement methods are necessary to advance the science of stakeholder engagement in research governance.

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