

An overview of Patient Advisory Councils and Community Advisory Councils in health care

Question

What are the best practices, lessons learned, and limitations of Patient Advisory Councils and Community Advisory Councils in health care settings?

Key Take-Home Messages

- Patient Advisory Councils and Community Advisory Councils promote patient engagement and the development of strategies and interventions to benefit the delivery of patient care; these collaborative councils are comprised of patients and health care providers who facilitate two-way communications regarding ongoing clinic operations (Patient Advisory Councils) (1, 2) and local community members who provide direct feedback on ongoing community health issues (Community Advisory Councils) (2–4).
- Appropriate representation of councils and increased patient engagement enhances the effectiveness of Patient Advisory Councils and Community Advisory Councils (5–7). Targeted strategies to recruit diverse populations include waiting room information booths (8), direct invitations from health care providers (9), and health registries (6).
- Patient engagement promotion techniques include providing council members with training and proper access to community health data (10). In addition, engagement increased when council members developed personal connections (11), council meetings and deliberations were held in a face-to-face setting (5, 12), and members received intensive training related to topics discussed at meetings (7, 13).

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- Incentives can be used to reward members for their participation in Patient Advisory Councils and Community Advisory Councils (2, 14), and can also be useful in reducing potential barriers restricting individuals from attending these groups (e.g. childcare, transportation) (2, 14). Incentives may increase representation and engagement of patients who would typically be affected by these barriers (9).
- Studies have highlighted a number of time constraint problems among councils. For example, the amount of time required to reach a consensus regarding a council decision may be higher than anticipated (10), which could become problematic due to the large amount of time and resources already required to run the groups (1, 15). In addition, implementation evaluations are not done for every intervention implementation; therefore, members do not always receive comprehensive feedback on the impacts of Patient Advisory Council and Community Advisory Council strategies on the delivery of patient care (5, 16–18).

! The Issue and Why it's Important

Patient Advisory Councils, more commonly referred to as Patient and Family Advisory Councils/Committees in Canada (19–21), are used to promote and achieve patient engagement and can improve health care clinic quality and the delivery of patient care (1). These councils are made up of patients and caregivers that regularly convene with health care workers and researchers to enhance the delivery of patient care (1). There are typically eight to 12 patients included in a Patient Advisory Council who remain on the council for six months to a year, with one individual designated to assist with the facilitation of meetings and management of council operations (2, 9). Patient Advisory Councils have been implemented in many high-income countries, including Canada (21–23), the U.S. (2, 24, 25), and member countries of the European Union (26, 27). Community Advisory Councils have similar sounding names to Patient Advisory Councils, though their purposes slightly differ (28). Community Advisory Council members are typically comprised of representative members of communities interested in volunteering their time to support research focused on enhancing the well-being of their community (3, 29). These clinic councils focus their efforts on the relationships between health care facilities and the community (2), providing feedback to health care providers regarding patient and population health concerns and interests based on community input (3, 4). This differs from Patient Advisory Councils, which facilitate two-way patient-clinic communication regarding everyday clinic operations (2). Overall, community councils are developed to identify gaps in and increase community engagement in a health care setting (18, 30), and to improve the health of a population (31). These councils have also been implemented in various high-income countries, including Canada (32), the U.S. (30, 31, 33), New Zealand

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(18), and Australia (28, 34).

Advancing best practices in health care with Patient Advisory Councils, which includes improving patient engagement and overall patient-centred care, can be accomplished by sharing and understanding patient and family health care perspectives and experiences through regular meetings with health care professionals (2, 22). Patients have reported unfavourable outcomes while receiving health care in the past, including poor communication and difficulties with the delivery of health care (35); thus communication and collaboration between patients and clinic staff to bolster the patient voice is important in enhancing the delivery of patient care (5, 36, 37). Community engagement has also been shown to help improve health outcomes in the health sector (18, 38). While Community Advisory Councils primarily include the participation of local community members and their perspectives, one of the main objectives of these groups is to advocate and implement policy to enhance the health of their community (2, 18). These clinic councils also focus their efforts on the relationships between hospitals and the community (2). Council members evaluate community input and give voice to their communities by providing advice on various initiatives (3, 4, 39). To improve health care initiatives, it is essential that the Patient Advisory Council and Community Advisory Council members communicate openly and negotiate with each other and clinic workers (1, 3, 40).

Patient Advisory Councils are known by a number of different names, including: patient and family advisory council (35), Patient, Family, and Public Advisors Council (23), patient advisory board (40), client council (27), client advisory council (41), and Patient Advocate Advisory Council (36). Additional names of Community Advisory Councils include: community council (42), Community Research Advisory Council (43), community advisory committee (30), community health councils (18), and Community Academic Council (31).

This review focuses on the impact of and approaches taken by Patient Advisory Councils and Community Advisory Councils in a health care setting. The best practices, lessons learned, and limitations of these groups are identified and evaluated.

What We Found

Best practices

Research has shown that the implementation of Patient Advisory Councils and Community Advisory Councils depends on the appropriate recruitment of comprehensive councils (8) and effective patient and community engagement and participation (5, 9, 10).

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Recruitment strategies

A Patient Advisory Council comprised of members that are representative of clinic patients can provide a platform for a broader, more diverse range of perspectives that may not have been considered (2, 9). Research has proposed several methods to successfully recruit a diverse group of patients, such as clinic-patient communication through emails and letters (2), clinic waiting room information booths (8), and invitations directly from health care providers (9). Passive recruitment of patients through the use of flyers, signs, and newsletters promoting Patient Advisory Councils has been conducted (2), though when the purpose is to recruit a more diverse population, this technique is avoided in favour of using direct communication between clinic staff and patients (9).

It is feasible to create a comprehensive Patient Advisory Council to benefit clinics and patient-care (8). One 2020 study conducted in Quebec City created two Patient Advisory Councils at two primary care practices that recruited patients, caregivers, clinicians, nurses, and managers, each council meeting six times in a one-year period to discuss and improve various clinic and patient care projects (8). Councils successfully collaborated and negotiated plans to improve patient-care and enhance the patient experience (8). However, the implementation of these plans was not reported in the published article (8). After the study period, the Patient Advisory Council members provided positive feedback on their experience (8). Overall, 66.7% of the patients believed the councils made an impact on clinic and patient care projects, and most members were satisfied with their participation on the council; on a scale from 1 to 10, the median was 8 (8).

One study published in 2011 discusses the use of health registries and community partnerships in Michigan to recruit marginalized populations in health research (6). To recruit older African Americans, a research volunteer registry for health research was developed with the assistance of a Community Advisory Board member and additional community outreach staff; researchers assessed how targeted community outreach activities were able to reach this population for the registry (6). Over a seven-year period, targeted community health education outreach programs increased the number of enrollees on the volunteer registry from 102 to 1,273 individuals (6). While this research did not concentrate on recruitment for a Community Advisory Board, the collaboration and communication conducted by Community Advisory Board members may assist in promoting and enhancing positive health outcomes through their contribution to community health-related research (6). Other studies have supported this evidence: researchers found that Community Advisory Councils help considerably in the recruitment of community members for community-based partnership research for marginalized populations (5, 6), and have enhanced the integrity and aided in the overall progress of these research projects (44, 45).

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Promoting patient and community engagement

Promoting patient engagement can have a positive impact on patient experiences and care by contributing to the quality of research at many different levels in the health care system (35), which can be improved using strategies discussed and implemented by Patient Advisory Councils and Community Advisory Councils (22, 46). Advice and strategies developed by the councils can be integrated into direct care, organizational design, and governance at the policy-making level in health care (5, 37, 47).

Engagement has shown to be critical in creating successful Patient Advisory Councils that produce successful interventions; for example, a study from 2016 describes how St. Alexius Medical Center in Illinois created a Patient and Family Advisory Council that developed many interventions to improve pain management delivery care (35). The strategies created by the Patient and Family Advisory Council over a one-year period were successful in improving pain management, where the engagement of council members was essential in the production of successful interventions (35). Developing expectations that council members serve as both advisors and decision-makers to improve the health of patients can also promote patient engagement (37).

Patient engagement can be improved with strategies carried out by Patient Advisory Councils. A 2019 systematic review evaluated the impact of Patient, Family, and Community Advisory Councils on health care systems, exploring various interventions used by the groups (5). The majority of studies were conducted in the U.S. (n=9), followed by Canada, Europe, and one study in India (5). Eighteen articles describing 16 studies were included in the review that examined different patient engagement strategies implemented at different levels of health care; overall, the review observed patient engagement at many levels of the health care system, finding that in-person deliberation was the most effective way to communicate with leadership in the health care community (5). While there are 16 studies observed in this systematic review, some examined groups that were not explicitly identified as Patient Advisory Councils (i.e., citizens panel, community health advisors) (5). Only studies that clearly observed Patient Advisory Councils from 2010 to present were considered and are listed immediately below (5).

- An observational study examined a Latino Family Advisory Board created at a pediatric health care practice that aided in the improvement of health care services and enhancement of patient engagement for low-income Latino families in the community (5, 9). Feedback from family members regarding community-based activities, clinic operations, and clinic-associated research projects and programs were communicated directly to the health care staff members on the Latino Family Advisory Board for two years (5, 9). This collaboration resulted in the distribution

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of new educational materials and implementation of effective interventions in the clinic to improve the health care experience for Latino families in the community (5, 9). Members were satisfied with their contributions to the Latino Family Advisory Board, and patient engagement was maintained throughout the duration of the two-year study (5, 9).

- A cluster randomized trial study published in 2014 analyzed a Patient and Family Advisory Council focused on policy-based interventions at six Health and Social Services Centers in Canada, with health care professionals and members of the public from these organizations participating in the council (5, 10). Patient and Family Advisory Council members were more effective and engaged with the council when: they had previously been patients and/or caregivers; they were involved in preparation meetings prior to convening with the Patient and Family Advisory Council; and they had access to community health data (5, 10). These strategies created an environment which enhanced the decision-making and implementation of health care policies in patient-care environments (5, 10).
- A 2016 article described a patient-dominated voting panel in the U.S. made up of ten individuals with rheumatoid arthritis created to involve patients in the development of clinical practice guidelines (5, 48). This panel communicated directly with specialized staff and a physician to create recommendations for various clinical questions related to rheumatoid arthritis, and their recommendations were subsequently compared to guidelines created by a group of physicians provided with the same questions (5, 48). The patient-dominated panel created recommendations for 16 of 18 questions, citing a lack of data as the reason for not creating recommendations for all (5, 48). Of the 16 recommendations, 13 were similar to the physician-dominated panel (5, 48). Different perspectives were observed when assessing risk; for example, the patient panel voted for a more aggressive therapy to achieve a favourable outcome of “feeling normal” (5, 48). However, the physician panel’s therapy recommended a less-aggressive treatment plan after considering that harmful long-term therapy outcomes may outweigh the benefits (5, 48). The study researchers highlight the importance of having engaged patients and health care providers working together, as both groups brought valuable perspectives and experience to policy-making in health care (5, 48).

Similar to the findings of the systematic review, studies published in recent years assessing interventions focused on improving patient engagement also had encouraging results. One study conducted

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from February to April 2017 in nine academic and community-based medical centres across the U.S. explored patient engagement strategies and barriers within Patient Advisory Councils (11). The research team organized and evaluated focus groups and interviews to assess the experience of Patient and Family Advisory Council members, leaders, and researchers with the councils (11). One notable finding in the study was that creating a “sense of community” and allowing the council members to connect on a personal level was fundamental to enhancing patient engagement (11).

Educational bootcamps have also demonstrated the ability to enhance patient and community engagement. A Community Advisory Council established in 2003 in Colorado engaged in an intensive 6-month educational colon cancer prevention boot camp to inform development of an intervention to enhance colon cancer screening (7). Following this training, the Community Advisory Council members reported being fully engaged in developing their intervention, with researchers highlighting the importance of community engagement and how council members approached the project differently after having attended the boot camp (7, 46). Overall, Community Advisory Council members attending training on the topic that they were tackling as a group increased their engagement and participation in all aspects of the intervention (7, 46). A second study, published in 2021, explored the outcomes of Community Advisory Council members utilizing a Boot Camp Translation (BCT) program, a community-based participatory research technique that translates evidence-based guidelines for the community regarding a health topic (46), to explore factors and barriers associated with effective asthma care (13). Using this method, council members enhanced their knowledge of asthma control, engaged stakeholders, and implemented community-preferred interventions to improve asthma care and raise awareness of communication gaps between patients and health care providers (13). Overall, the Boot Camp Translation program increased patient and community engagement to create successful interventions to tackle health inequities among their community (13).

A 2017 study exploring community stakeholder engagement in a Community Advisory Board at the University of North Carolina emphasized how members benefitted from in-person meetings, especially in early stages of the formation of the council (3). Later on, the researchers found that the convenience of over-the-phone conference calls and individual communication with other board members maintained stakeholder engagement in the council (3). Similar to this study, a randomized study published in 2003 evaluated policy-based interventions developed by a citizen panel, which was made up of community organization representatives (5, 12). Overall, community engagement was higher in settings where council topics were deliberated face-to-face as a collective group (5, 12). In comparison, mailed surveys, phone calls, and one-on-one meetings appeared to be less effective (5, 12).

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Lessons learned

A previously mentioned study evaluating a Latino Family Advisory Board in the U.S. highlighted how the participation of low-income Latino families in the council helped counter discrimination experienced in health care (5, 9). Incentives, such as meals and childcare during the meeting, increased and sustained the engagement and participation of Patient Advisory Council members (9). Other studies echo these findings: financial compensation can support patient participation and/or reward Patient Advisory Council members for their time and contributions, which may alleviate barriers—such as childcare and transportation—that restrict patients from volunteering in these councils (2, 14). However, it may not always be feasible for a clinic council to provide these incentives (9).

Building Patient Advisory Councils and Community Advisory Councils with adequate representation and developing engaging relationships with local community leaders are valuable lessons learned by researchers looking to create or improve these groups (8, 49). Appropriate representation is required to tackle health inequities when utilizing Patient Advisory Councils and Community Advisory Councils to promote patient engagement (3, 8). Patient engagement strategies catered to groups of people with higher education and increased social advantages target only a subset of the affected population, therefore would not be inclusive and comprehensive (8). Proper recruitment methods have the potential to create representative councils, and studies have highlighted that this can be accomplished with waiting room information booths (8) and direct communication with health care providers (9). Literature has suggested that local leaders are in a position to aid in developing interventions with a Community Advisory Council as they are often well-informed of their community's social and political atmosphere (49-52).

In addition, one study published in 2017 found that it took six months to one year for all members of their Community Advisory Board to feel as if their voice was being heard (3). The importance of individuals personally connecting with their fellow board members assisted them in feeling that their voice was valued (3). This finding was also reflected in a 2018 study with Patient and Family Advisory Councils: the research suggested members were more engaged with the council when they had personal connections with other Patient and Family Advisory Council members (11).

Limitations

A number of limitations have been identified with the development and evaluation of Patient Advisory Councils and Community Advisory Councils. Many studies identified time as a primary problem; a previously mentioned study discussing the engagement of Patient

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Advisory Council members in Canada highlighted that member participation was limited due to the time constraints faced by the group (8). Another study published in 2014 indicated how groups took a long time to reach a consensus on various decisions, stretching the amount of time needed to tackle all projects (10). It also takes a great deal of time for councils to complete projects, as recruiting patients, attending meetings, and developing interventions takes a considerable amount of time and other resources (1, 15).

A 2014 study in the Netherlands investigated the voices of older patients in a Dutch hospital (27). Interestingly, every health care institution in the Netherlands is obliged to have a client council and its rights are legally established (27). Despite comprising a large portion of the hospital population, the voices and concerns of older patients are often given little attention (27). The study examined client councils and patient participation in hospital care and raised the issue that members are not familiar enough with hospital operations and are taking a more passive role due to the busy nature of the council (27). The researchers observed that older voices do not have a clear impact on the activities in the client councils, expressing that “[w]hen equality is associated with sameness, people are only treated as equal when they resemble the powerful” (27). Understanding the equality of outcome, in which all individuals are seen as equals on the basis of being a care receiver rather than on the basis of rights, may help improve the practice of the client council (27). Client council members in the study describe other time constraints: for example, the hospital Board of Directors provided the council with late proposals on multiple occasions. This resulted in members being unable to adequately inspect documents and feeling as if their only choice was to accept the proposals presented to them (27). Splitting up tasks among client council members may help the council take a more direct role and increase involvement (27). Finally, this study suggests that well-educated individuals with similar perspectives as health care providers are attracted to participate in the client council (27). Council members strongly agree with each other, and differences in perspectives between council members are suppressed (27). Despite the useful recruitment strategies available for creating representative Patient Advisory Councils and Community Advisory Councils (5, 6, 8), underrepresentation of patients and communities remains prevalent (16, 53).

Other research has found that members of both Patient Advisory Council and Community Advisory Council are unsure if their contributions are having a positive impact on the delivery of patient care (1, 18, 34). A common challenge is that council members do not typically conduct research related to the topics discussed during the meetings with health care professionals, and it is not mandatory for researchers and health care workers to follow the advice provided by councils related to patient experiences (40).

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Factors That May Impact Local Applicability

There is no consensus regarding proper council representation and interventions and strategies developed by Patient Advisory Councils and Community Advisory Councils may not possess a diverse range of perspectives and may not always be generalizable to the desired target populations (16, 53). A majority of studies examined were conducted outside of Canada. Health care systems differ across jurisdictions, therefore implementing strategies in the local context may require the participation and involvement of different organizations and levels of government. Finally, Patient Advisory Councils and Community Advisory Councils are referred to by a number of different names globally. While the composition, main objectives, and functions of the councils appear to be the same or highly similar, groups may approach projects differently. This could pose challenges for councils attempting to reproduce the integration of strategies and interventions found in the literature into their communities and local clinics.

What We Did

We searched Medline (including Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE® Daily and Ovid MEDLINE®) using a combination of terms (client* adj3 council* or patient* adj3 council* or community adj3 council*) in titles or abstracts. Searches were conducted on February 22, 2022 and results limited to English articles published from 2010 to present. Studies from low- and middle-income countries were excluded. Reference lists of identified articles were also searched. Google (grey literature) searches using different combinations of these terms were also conducted. The searches yielded 317 references from which 53 were included.

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