


# THE VOICE OF PATIENTS AND FAMILIES

## A Toolkit to Improve Diversity in Patient and Family Advisory Councils: A New Method to Advance Health Equity

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The Institute of Medicine (2001) identifies equity as one of six essential components of health-care quality. However, many health-care organizations lack a formal method to deeply understand and evaluate diverse patient and family experiences. Understanding care experiences of patients and families from minority racial and ethnic groups is essential to improving pervasive health disparities and to making health care more equitable. This article describes the creation of a toolkit aimed at strengthening health-care organizations' abilities to advance health equity through patient and family advisory councils (PFACs). This resource, cocreated with representatives from diverse PFACs, identifies and promotes strategies to recruit and retain diverse representation in advisory councils.

**Keywords:** patient- and family-centered care; patient and family advisory councils; diversity; inclusion; health equity; toolkit



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The Institute of Medicine (IOM; 2001) identifies equity as one of six essential components of health-care quality. Equity is defined as “providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status” (IOM, 2001, p. 3). However, in the U.S. health-care system, health equity is lacking. Racial and ethnic minorities receive poorer quality care and have less access to health-care services, which contributes to health disparities and poor outcomes (Goldstein, Elliott, Lehrman, Hambarsoomian, & Giordano, 2010; Hall & Fields, 2013). Provider bias, stereotyping, and prejudice also influence health disparities (IOM, 2003; Weech-Maldonado et al., 2015).

Many health-care organizations lack a formal way to deeply understand and evaluate diverse patient and family experiences. However, understanding care experiences of patients and families from minority racial and ethnic groups is essential to improving pervasive health disparities and to making health care more equitable. One evidence-based strategy to improve connection between patients, families, and health-care professionals is patient and family advisory councils (PFACs; Bookout, Stafflieno, & Budzinsky, 2016). When mindfully created, PFACs can strengthen partnership between staff and diverse patients and families, increase opportunities for organizations to meaningfully engage with communities they serve, and improve the ability of health systems to truly meet the needs of all health-care consumers, not just the majority demographic group (Institute on

Assets and Social Policy, 2016). For example, an urban primary care practice in Baltimore found that Spanish-speaking patient and family advisory meetings enabled participants to raise issues that were markedly different than problems discussed during meetings held in English. Advisory members discussed instances of marginalization in health care and highlighted how their experience as board members countered perceptions of discrimination, enabling them to participate more fully in the health-care system (DeCamp et al., 2015). This diversity-sensitive PFAC provided the organization with invaluable insights on how to improve services to address this patient population's unique needs.

PFACs are typically composed of patients and family members who meet periodically with health-care staff to share personal stories of care experiences (Bookout et al., 2016). Ideally, PFACs should reflect the diversity of the communities those health-care organizations serve, highlighting the racial, ethnic, socioeconomic, religious, gender, cultural, and educational demographics present in the community. While the literature is replete with organizational best practices for recruiting members to participate in PFACs, it does not adequately address the importance of diversity, particularly ethnic or racial diversity, in creating a PFAC.

Health care would benefit from a toolkit to enhance PFAC diversity. Toolkits are an effective resource for putting the best evidence into practice to improve outcomes (Yamada, Shorkey, Barwick, Widger, & Stevens, 2015). They are a "one-stop shop" for essential information, which facilitates a deliberate approach to implementing interventions for a desired outcome (Tydings, 2014).

The purpose of this article is to describe the creation of a toolkit aimed at strengthening health-care organizations' abilities to advance health equity through PFACs. This resource, cocreated with representatives from diverse PFACs, identifies and promotes strategies to recruit and retain diverse representation in advisory councils. Cocreation theory, or code-sign theory, was used as the framework in partnering with diverse PFACs. This approach places the end user (i.e., PFACs) in an "expert" position to create knowledge, generate ideas, and develop concepts (Sanders & Stappers, 2008). Codesign allows solutions to be informed and created by those most impacted; systems are most effective when those closest to care own the decisions that are made there (Porter-O'Grady & Malloch, 2015).

## METHODS

The community partner for this quality improvement (QI) project was a nonprofit health-care consulting agency in Maryland. An organizational needs assessment identified an opportunity to develop and incorporate a diversity and inclusion best practice toolkit into the organization's resources to improve the process of recruitment and retention of diverse advisors. Organizational leaders acknowledged that their clients cited challenges in sustaining representative diversity, particularly racial and ethnic diversity, of advisors and employees who volunteer to participate in PFACs.

### Developing the Team of PFACs

Using codesign theory (Sanders & Stappers, 2008) as the foundation, this best practice toolkit would be developed in partnership with a select group of PFACs, primarily those who endorsed moderately diverse representation. Participating PFACs were from Washington state, North Carolina, Virginia, Pennsylvania, and Montreal, Canada, and endorsed diversity in race, ethnicity, religion, gender, language, socioeconomic status, education, ability, and sexual orientation. Diversity in these aspects ensured that voices and perspectives of advisors from various backgrounds were well represented in the toolkit's creation. A health literacy content expert was also consulted to provide guidance in modifying the toolkit for accessibility and readability.



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Due to lack of an interpreter, non-English speaking PFACs were unable to participate; undoubtedly, their perspective would have been invaluable in toolkit development.

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## Ethical Considerations

According to the University of Minnesota's online Institutional Review Board (IRB) determination tool, this project was Quality Assurance (QA)/QI, not human subjects research. No further IRB review or approval was required.

## Overview of Methodology

The author reviewed online materials from the community partner specific to recruitment and retention of advisors. These documents were foundational in developing the best practice toolkit. An OVID Medline search used keywords patient, advisory council, advisory group, recruit, divers, and advisory board, individually and combined. Primary and secondary sources were reviewed, and 30 articles were selected for inclusion in the toolkit, using a literature review matrix to organize the articles' content based on themes. Themes were strategies for diverse recruitment and retention, barriers to diversity retention, and ways to build a culture of organizational inclusivity. The literature matrix content was synthesized with documents from the community partner to create the first draft of the toolkit.

Implementation consisted of three distinct plan-do-study-act (PDSA) cycles. At the beginning of the first PDSA cycle, the first draft of the toolkit was e-mailed to PFAC groups for review. The author then conducted meetings with PFACs to obtain feedback on the toolkit. Participant responses about the toolkit were qualitatively analyzed into themes and revised based on comments. In the second and third PDSA cycles, participating PFACs were e-mailed the second and third iterations of the PFAC toolkit along with the link to a survey that asked for specific feedback, which was used to create the final version.

## RESULTS

Table 1 shows responses from participants after the third and final toolkit iteration.

### Data Analysis

The results revealed that codesign theory was used effectively in engaging participants, as most respondents indicated they felt heard, respected, and useful during the project. The codesign framework provided an avenue to incorporate a necessary perspective, the diverse patient's voice, into the toolkit development.

The first iteration of the toolkit was 26 pages. It was written in an academic tone and did not have any color or pictures. It also included resources from the community partner specific to selecting and orienting new advisors. With feedback from participating PFACs, the final draft of the toolkit was 14 pages. It was less formal in tone, had vibrant colors, and included pictures of diverse individuals.

The toolkit's content also changed throughout the project cycle. The first draft included more resources from the community partner. The participating PFACs recommended including only information pertinent to diversity and inclusion. They also suggested creating diversity and inclusion checklists; these checklists were featured and refined in the second and third drafts of the toolkit.

The toolkit also provided participants with new resources to increase PFAC diversity and inclusion, as most respondents indicated that resources in the toolkit could be used to influence their council's diversity and all indicated at least one tool they could use. The *Inclusivity Self-Assessment Checklist for Advisors* (Jones, 2018) was the resource most selected by respondents as a tool they could use to increase their council's diversity and inclusion. This tool asks advisors to assess how inclusive their PFAC is, including how welcome they feel in their advisor role. The popularity of this tool highlights how PFACs care about the individual perspectives which can provide insight into improving the council's diversity and inclusion.

**TABLE 1. Post-intervention Survey Results**

Survey Question	Responses indicating “Yes”
Overall, does this resource highlight the importance of diversity and inclusion for PFACs?	19 (95%)
Were the tools (checklists, action plans, sample flyers, background information) included in the resource useful?	18 (90%)
Do you think your PFAC would use these tools to increase diversity and inclusion in your council?	16 (80%)
Do you feel like your perspective was heard and respected in creating this resource?	18 (90%)
Do you feel like your comments and/or your PFACs comments were used to modify the resource throughout the course of the QI project?	18 (90%)
Please indicate at least one strategy or tool you have learned from this resource that you could use to increase diversity and/or inclusion in your PFAC.	Self-assessment checklist for advisors: 9 (45%) Diversity action plan: 8 (40%) PFAC self-assessment checklist: 8 (40%) One of the recruitment strategies for diversity: 8 (40%) One of the retention strategies for diversity: 4 (20%)
Number of respondents who indicated at least one strategy or tool they have learned from the resource to help increase diversity and/or inclusion in their PFAC	20 (100%)
Number of respondents who indicated two or more strategies or tools they could use to improve PFAC diversity/inclusion	8 (40%)

Note. PFAC = Patient and family advisory council; QI = quality improvement. (n = 20), n (%).

## DISCUSSION

This QI project successfully synthesized best practice strategies to create a toolkit for recruiting and retaining diverse participants. It highlighted the importance of diversity and inclusion in PFACs and provided useful information to participants to increase diversity in their councils. In this project, codesign was used as a framework to draw from advisors’ expertise to design the diversity and inclusion toolkit. Despite geographic distance between the project director and PFACs, advisors felt engaged in the project. Throughout the project, the project director highlighted PFAC strengths and showed appreciation for their knowledge. This paved the way for codesign to be used effectively. Collaboration between PFACs and the project director was at its best when expectations and responsibilities were clear. This was best shown when surveys were used in the second and third PDSA cycles to obtain feedback. Feedback from participants increased with this kind of structure. This highlights that codesign can be a useful strategy for leaders who are collaborating with teams in different places. The popularity of the *Inclusivity Self-Assessment Checklist for Advisors* highlights that councils are interested in understanding advisors’ individual experiences to improve PFAC diversity and inclusivity.

### Limitations

Although the toolkit was developed successfully, there were several limitations to the project. Not all participating PFAC advisors completed the final survey to provide feedback

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on the toolkit. Thus, the final results reflect the views of those who chose to participate, which may differ from those who did not. This was a QI project, so the findings are not generalizable to other organizations. However, this project does demonstrate application of best practices to improve current processes.

Additionally, the project director and project advisors all lived in different parts of the country; therefore none of the scheduled meetings were face-to-face (most meetings were conducted on the telephone, but one group did have access to video conferencing). This geography made it challenging to initially establish camaraderie with participating PFACs. Nearly all meetings were completed during PFACs scheduled meeting times. While this ensured convenient timing, it only allowed short periods of time to discuss the project and provide updates.

Outside of meetings with PFACs, project communication was conducted mostly online, which required frequent follow-up between the project director and key contacts via e-mail. Lastly, due to lack of an interpreter, non-English-speaking PFACs were unable to participate. Undoubtedly, this perspective would have been invaluable in toolkit development. Including non-English-speaking PFACs may have resulted in a slightly different toolkit with their insights.

## CONCLUSION

PFACs that intentionally incorporate diversity have the potential to help address health disparities and negative patient experience by lifting up the voices of diverse patients. Diverse perspectives help create and/or improve services, which address these patients' unique needs to improve our health-care system. The diversity and inclusion toolkit created in this project may be used by other PFACs who want to enhance diversity and inclusion in their councils. Our community partner published the toolkit on their website last spring. The toolkit can be found at this link: <http://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf>.

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**Disclosure.** The authors have no relevant financial interest or affiliations with any commercial interests related to the subjects discussed within this article.

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