

## **Diverse Voices Matter: Improving Diversity in Patient and Family Advisory Councils**



# Increasing Diversity In Patient and Family Advisory Councils

## Why Does Diversity Matter?

Many healthcare organizations are looking for better ways to understand diverse patient and family experiences.. Research shows that racial and ethnic minorities often receive poor quality care and have worse access to services. This can lead to poor health for these groups. Knowing how patients and families from minority racial and ethnic groups experience the healthcare system is important to eliminating health gaps.

## Diversity in PFACs

Diversity helps your patient and family advisory council (PFAC) have a wider range of views and look like the patients you care for. Some councils have trouble inviting people from different backgrounds, particularly race, even when their community is diverse.

## What Is Diversity?

Making your council more diverse means welcoming people from different backgrounds, like race and ethnicity. Other differences you may want to consider are sexual orientation, gender, age, financial situation, physical and mental ability, and schooling,

If your council is responsible for more than one setting, you may want to find advisors from different locations such as in the hospital, clinic, home health, or hospice. Advisors from different departments, such as women's, children's, rehabilitation, or cancer services can also bring new views to your group.



## Finding Diverse Advisors:

# Where Do We Start?



### Who Is On Your Council?

Look at the current makeup of your council. You may ask: Are advisors like the patients we serve? If there are big differences between who is on your council and who is served in the hospital, this may be a sign that you need to work on finding more diverse advisors. Where you live and the community your organization cares for will decide what areas of diversity you need to work on.



### Is Your Council Welcoming?

As you look at how diverse your council is, it's also important for you to think about how welcoming your group is to diversity. This means asking hard questions with your team about how open you are to differences in view, lifestyles, and background. Knowing where you are will help you to create the best environment for new people to join your group.




### Understand Current Advisors' Experiences

Talking with current advisors and patients about what is it like to be cared for in your organization will allow you to learn more about what work your group should do. Patient surveys can also shed light into different care experiences. Once you know your current state, you can make a plan to create a more welcoming and diverse group.

---

**Creating a diverse group that looks like patients served by the healthcare system is key to hearing perspectives that makes health better for all.**





# Finding Diverse Advisors: How?



To create a diverse group that comes from different backgrounds, you might try:

- Asking community leaders for PFAC referrals
- Creating maps of racial and ethnic clusters to find community centers
- Getting to know the leaders within the community
- Asking local artists to help create PFAC materials in the language and culture of the community
- Going to community meetings to develop relationships
- Talking about advisor opportunities at community events.
- Creating a separate PFAC if you have a large patient population that does not speak English, (e.g., Bayview at Johns Hopkins University and Children's Mercy in Kansas City have Latino PFABs)

# What Else Can We Do To Find Diverse Advisors?

- Hang flyers asking people to join your council in the community. Good places are doctor's offices, schools, hair salons, bodegas, coffee shops, churches, temples, mosques, social service agencies, community festivals, gas stations, and grocery stores
- Put information about advisor opportunities in your patient satisfaction surveys
- Ask doctors, nurses, staff, public relations, community partners, or current advisors for people they think would be a good fit for the council
- Talk about the council in your organization's newsletters and website
- Talk about or present advisor opportunities at community events
- Ask patient or family networks or support groups for referrals
- Place ads in the local radio, TV, newspaper, and community newsletters
- Create a website for your council that tells how interested advisors can join



# Keeping Diverse Advisors Engaged : How?

Once your patient and family advisory council is diverse, it is important to keep your new members interested and involved. This may be hard to do. One key to maintaining a diverse council is creating a sense of community.



A study by Kaiser and colleagues found that a diverse focus group stayed in their program due to the **respect, good will, support, camaraderie,** and **fellowship** they experienced within the group and the **sense of service to others** they received from participating.

Other strategies include:

- **Develop relationships with PFAC members by hosting group activities outside of PFAC meetings**
- **Include relationship-building ice breaker activities in PFAC meetings (such as “getting to know you” questions)**
- **Offer new members time to talk with the PFAC chair after meetings to see how they are adjusting and ask for ideas for improving their experience**
- **Assign an experienced advisor as a mentor or PFAC buddy to new members**
- **Create a PFAC portal (like Facebook) to stay connected and updated on projects/initiatives as well as personal events such as upcoming surgeries or birthdays**
- **Get to know each member’s personal story, such as previous work and life experiences**
- **Get to know each member’s interests for the PFAC, like organizing events, environmental changes, finance, strategic planning, or brainstorming**
- **Find out and use each member’s preferred method of communication for updates ( e.g. phone, text, email)**
- **Make sure two-way communication is maintained**



# What Else Can We Do To Keep Diverse Advisors Engaged?

- **Brainstorm to hear about projects that advisors think would be impactful**
- **Connect advisors with the people in the organization who can help them develop ideas into reality (e.g. invite social work and chaplaincy to help develop a visiting program for patients without family or friends nearby)**
- **Provide members with taxi vouchers, meals, refreshments, and/or childcare during the meeting**
- **Allow flexible membership, including use of technology for online or telephone participation**
- **Hold meetings at different times to fit schedules, including on and off site**
- **Conduct occasional informal and formal evaluations of the PFAC as a group**
- **Let advisors drive the PFAC agenda**
- **Make PFAC meetings more hands-on**
- **Review key PFAC documents such as recruitment materials, charter/bylaws, annual report templates as new members become familiar with the PFAC to decide how these can be changed to be more inclusive**
- **Provide members with occasional token of appreciation such as dinner or a gift card**
- **Use a visual aid or flip chart to facilitate group conversation and promote a sense of community**
- **Make sure language interpreters are at meetings as needed**
- **Make sure all advisor voices are heard and respected**
- **Teach team members (PFAC and outside staff) about the advisor role and its importance**



# What Are The Hurdles We Might Face In Recruiting and Retaining Diverse Advisors?

While recruiting to improve diversity in your PFAC, it is good to consider these barriers. Knowing the challenges you may face can help you create solutions to address them.

## Common reasons for difficulty in recruiting diverse members:

- **Mistrust of the healthcare system**
- **Thinking that they will not be respected in their role**
- **Feeling powerless or that they lack influence**
- **Unable to take off time from work**
- **Unreliable transportation**
- **Unable to participate due to medical problems**
- **No resources for interpreters**
- **Not knowing what the advisor role is**
- **Using recruitment materials that are not culturally appropriate**
- **Not seeing results of their work come through**

Diverse members should actively participate in the dynamics of your group. A **welcoming environment may help increase** feelings of inclusion, or **feeling like one belongs**. This in turn, may help reduce disinterest and advisors leaving the group.

However, a community, even when diverse, may not be inclusive if diverse members perceive they have unequal power, limited involvement, or a silenced voice. For this reason, it is important that diverse members are not asked to join a PFAC only to improve the physical makeup of the group.



# Diversity and Inclusion Tools for Your Patient and Family Advisory Council

The next section has several tools you can use to improve diversity and inclusivity in your PFAC. These tools are:

- **A checklist to determine how welcoming your PFAC is (p. 10)**
- **An advisor checklist that can be used to see how welcomed advisors feel in your group (p. 11)**
- **Sample advisor recruitment flyers from established and diverse councils in Philadelphia, PA and Augusta, GA (pp. 12-14)**
- **A sample action plan to increase diversity (p. 15)**



# Inclusivity Self-Assessment Checklist for Patient and Family Advisory Councils

This checklist serves as an assessment tool to determine where your PFAC is in your journey towards inclusivity and diversity. This is not a full list of all things that can be done, but a starting point for you to discuss with your PFAC the areas related to diversity that need to be addressed.

- Is your PFAC reflective of your patient population?
- Has your PFAC evaluated its diversity?
- Has your PFAC reviewed your organization's patient experience data to screen for disparities?
- Has your PFAC partnered with community organizations to recruit more diverse participants?
- Do you have PFAC resources available in the languages of your patient population?
- Are diverse members' voices respected?
- Does the PFAC assess how often ideas and feedback from diverse members result in changes and improvements?
- Has your PFAC incorporated diversity into your mission, vision, and values?
- Have you changed PFAC policies to be more inclusive?
- Are PFAC meetings held during times that are convenient for advisors (i.e. not during typical business hours)?
- Do you have online or phone options for members to engage in meetings?
- Does your PFAC staff members reflect the patient population that is served?
- Does your PFAC have conversations about diversity?
- Has your PFAC analyzed the barriers for lack of participation of diverse members?
- At an organizational level, is there executive level support for diversity efforts?
- Is your PFAC conducting or participating in diversity, health equity, or implicit bias training?
- Does your PFAC encourage and value input of people from diverse perspectives and backgrounds?
- Does your PFAC welcome and celebrate differences?
- Does your PFAC assign a mentor to new members to help them feel welcome?



# Inclusivity Self-Assessment Checklist for Advisors

This is a checklist for you to assess how inclusive your PFAC is, including how welcome you feel in your advisor role. This is not a full list of questions you may ask, but a starting point for you determine if you feel embraced as an advisor.

- Does your PFAC have a diverse group of members?
- Is diversity welcome in your PFAC?
- Do you feel welcome in your PFAC?
- Do you feel respected in your role as an advisor?
- Do you feel that your voice matters in your PFAC?
- Do you feel included in PFAC decision-making?
- Do you feel like all advisors have an equal part in decision-making?
- Are differences celebrated in your PFAC?
- Are your PFAC's policies inclusive?
- Are PFAC resources available in your preferred language and at a level you can understand?
- Were you mentored as a new advisor?
- Do you receive coaching or training to keep strengthening your skills as an advisor?
- Do you feel like the leaders and other members of your PFAC know and value you as a person?

**Note:** If you answered “NO” to 3 or more items, you may want to talk with the leader of your council about your responses.



# Calling All Patients Now Recruiting

Share your thoughts and ideas

We are seeking patients who are willing to commit time to join the

## PATIENT AND FAMILY ADVISORY COUNCIL

- As a member of the council, you can share your point of view, perspective, and experience as we continue to improve the patient experience and deliver more effective care
- Commit to come to a meeting in July, September, & November 2014 at a locations on the Jefferson Campus



We value what you think. Be a part of something great!

QUESTIONS? Ask your Provider or contact:

**Amy Burzinski at 215-955-2360 or amy.burzinski@jefferson.edu**

*Our clinical practice has achieved the highest recognition (Level 3) for Physician Practice Connections–Patient-Centered Medical Home (PPC-PCMH) from the National Center for Quality Assurance (NCQA).*



**Department of Family & Community Medicine  
Thomas Jefferson University**

JFMA PATIENT & FAMILY  
ADVISORY COUNCIL  
215-955-2360 or  
amy.burzinski@jefferson.edu

JFMA PATIENT & FAMILY  
ADVISORY COUNCIL  
215-955-2360 or  
amy.burzinski@jefferson.edu

JFMA PATIENT & FAMILY  
ADVISORY COUNCIL  
215-955-2360 or  
amy.burzinski@jefferson.edu

JFMA PATIENT & FAMILY  
ADVISORY COUNCIL  
215-955-2360 or  
amy.burzinski@jefferson.edu

JFMA PATIENT & FAMILY  
ADVISORY COUNCIL  
215-955-2360 or  
amy.burzinski@jefferson.edu

JFMA PATIENT & FAMILY  
ADVISORY COUNCIL  
215-955-2360 or  
amy.burzinski@jefferson.edu

JFMA PATIENT & FAMILY  
ADVISORY COUNCIL  
215-955-2360 or  
amy.burzinski@jefferson.edu

JFMA PATIENT & FAMILY  
ADVISORY COUNCIL  
215-955-2360 or  
amy.burzinski@jefferson.edu

# Are you a Patient at Jefferson Family Medical Associates?

We are currently recruiting interested patients and their families to become members of the

## PATIENT AND FAMILY ADVISORY COUNCIL

**WHAT:** We are seeking patients who can help transform our practice to ensure the optimum patient experience with delivery of the highest quality of care. We want you and your family to join in the process of care as full members of the healthcare team.

**WHEN:** Commit to attend a meeting in **July**, **September**, and **November 2014**

**WHERE:** Location on Jefferson Campus

**We value what you think. Be a part of something great!**

Questions? Ask your Provider or contact:

**Amy Burzinski** at **215-955-2360** or **amy.burzinski@jefferson.edu**

*Our clinical practice has achieved the highest recognition (Level 3) for Physician Practice Connections–Patient-Centered Medical Home (PPC-PCMH) from the National Center for Quality Assurance (NCQA).*



**Department of Family & Community Medicine  
Thomas Jefferson University**





# We Want YOU

Augusta University Medical Center has Patient and Family Advisory Councils that want people like you to help us improve our patient's experience. We are looking for patients and family members who can:

- Share ideas in a positive way
- Respect others
- Listen
- Work with others to make AU Medical Center better
- Make a difference at AU Medical Center

For more information about becoming a Patient/Family Advisor, contact Naomi at [nawilliams@augusta.edu](mailto:nawilliams@augusta.edu) or 706-721-0472.



**Health**  
AUGUSTA UNIVERSITY

[augustahealth.org](http://augustahealth.org)



## CREATE YOUR DIVERSITY ACTION PLAN

Overall Goal: <b>Recruit and retain diverse advisors</b>			
<b>Action</b>	<b>Who Should Be Involved?</b>	<b>Questions to Ask</b>	<b>Additional Steps to Take</b>
<b>Prepare for change.</b>	PFAC advisors and staff*	Does my council have a culture that embraces diversity?	<ul style="list-style-type: none"> <li>- Assess PFAC support and commitment to diversity</li> <li>- Assess status of diversity in PFAC by reviewing patient population demographics, community demographics, and PFAC demographics</li> <li>- Assess PFAC inclusivity (See checklist)</li> <li>- Be open to honest conversations about any history of racism, discrimination, and/or oppression that exists in your area or organization</li> </ul>
<b>Determine what change is needed.</b>	PFAC advisors and staff*	Where can we improve diversity and inclusivity?	<ul style="list-style-type: none"> <li>- Learn the lived experience of diverse patients and advisors in your organization by discussing with them what it is like to access care</li> <li>- Review patient experience surveys</li> <li>- Determine if diversity, implicit bias, and/or cultural competency training is required for staff and advisors</li> </ul>
<b>Embark on the change.</b>	PFAC advisors, staff*, and community organizations	Who should we partner with?	<ul style="list-style-type: none"> <li>- Meet with community leaders to first build a relationship and discuss the PFAC purpose</li> <li>- Ask how best to connect with the community to communicate advisor opportunities</li> <li>- Find out what supports are needed for individuals to participate and secure resources (e.g. transportation, interpreters, child care)</li> <li>- Advertise PFAC opportunities in community settings and organization's newsletters</li> </ul>
<b>Implement the change.</b>	PFAC advisors, staff*, and new advisor mentors	How do we on-board new advisors?	<ul style="list-style-type: none"> <li>- Talk with potential advisors about their role and responsibilities</li> <li>- Have applicants go through your PFAC's screening and application process</li> <li>- Assign a mentor to new advisors to provide support</li> </ul>
<b>Reinforce the change.</b>	PFAC advisors, staff*, advisor mentors, and community organizations	How can we create a culture where diverse advisors feel respected, welcome, and engaged?	<ul style="list-style-type: none"> <li>- Get to know each member, their story, background, and interests</li> <li>- Engage in relationship building activities (like "getting to know you" questions)</li> <li>- Regularly talk with advisors to determine if their participation is what they expected</li> <li>- Conduct periodic informal and formal evaluation of the council and its members' perceptions to determine effectiveness (See PFAC and advisor checklists)</li> <li>- Ensure two-way communication is maintained and communication preferences are respected</li> <li>- Hold meetings at convenient times to accommodate varied schedules; include phone and online meeting options</li> </ul>

**Note:** Staff refers to PFAC staff, such as organizational leaders who sponsor the council.



**THIS TOOLKIT WAS CREATED IN PARTNERSHIP BY:**

**KENDRA JONES BSN, RN**

*DNP student in Health Innovation and Leadership at the University of Minnesota*

Collaborating patient and family advisory councils:

- **SIDNEY KIMMEL MEDICAL COLLEGE AT THOMAS JEFFERSON UNIVERSITY**

*Philadelphia, PA*

- **MCGILL UNIVERSITY HEALTH CENTRE**

*Montreal, CA*

- **VIRGINIA COMMONWEALTH UNIVERSITY HEALTH**

*Richmond, VA*

- **PEACEHEALTH MEDICAL GROUP**

*Eugene, OR*

- **VIDANT MEDICAL CENTER**

*Greenville, NC*

## RESOURCES

Bleich, M.R., MacWilliams, B.R., & Schmidt, B.J. (2015). Advancing diversity through inclusive excellence in nursing education. *Journal of Professional Nursing*, 31(2), 89-94. doi: <http://dx.doi.org/10.1016/j.profnurs.2014.09.003>

Bookout, M.L., Staffileno, B.A., & Budzinsky, C.M. (2016). Partnering with a patient a family advisory council to improve patient care experiences with pain management. *The Journal of Nursing Administration*, 46(4), 181-186. doi: 10.1097/NNA.0000000000000328

Buse, K., Bernstein, R.S., & Bilimoria, D. (2016). The influence of board diversity, board diversity policies and practices, and board inclusion behaviors on nonprofit governance practices. *Journal of Business Ethics*, 133, 179-191. doi: 10.1007/s10551-014-2352-z

Coutinho, M.T., Koinis-Mitchell, D., Kopel, S.J., Romero-Bosch, L., Lobato, D., McQuaid, E.L., ... & Fritz, G.K. (2014). Factors associated with recruitment and retention of diverse children with asthma. *Children's Health Care*, 43, 132-150. doi: 10.1080/02739615.2013.837821

Dilworth-Anderson, P., & Cohen, M.D. (2010). Beyond diversity to inclusion: Recruitment and retention of diverse groups in Alzheimer's research. *Alzheimer Disease Associated*, 24(3), S14-18.

Ejiogu, N., Norbeck, J.H., Mason, M.A., Cromwell, B.C., Zonderman, A.B., & Evans, M.K. (2011). Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the healthy aging in neighborhoods of diversity across the life span study. *The Gerontologist*, 51(51), S33-S45. doi: 10.1093/geront/gnr027

Fredette, C., & Bradshaw, P. (2012). The inclusive nonprofit boardroom: Leveraging the transformative potential of diversity. *Nonprofit Quarterly*. Retrieved from <https://nonprofitquarterly.org/2012/12/29/the-inclusive-nonprofit-boardroomleveraging-the-transformative-potential-of-diversity/>

Gonzalez-Guarda, R.M., Jones, E.J., Gillespie, G.L., & Bowen, F. (2017). Advancing nursing science through community advisory boards: Working effectively across diverse communities. *Advances in Nursing Science*, 40(3), 278-288. doi: 10.1097/ANS.000000000000167

Goldstein, E., Elliott, M.N., Lehrman, W.G., Hambarsoomian, K., & Giordano, L.A. (2010). Racial/ethnic differences in patients' perceptions of inpatient care using the HCAHPS survey. *Medical Care Research and Review*, 67(1), 74-92. doi: 10.1177/1077558709341066


Hall, J.M., & Fields, B. (2013). Continuing the conversation in nursing on race and racism. *Nursing Outlook*, 61(3), 164-173. doi: <http://dx.doi.org/10.1016/j.outlook.2012.11.006>

Hinjosa, M.S., Kadviar, H., Fernandez-Baca, D., Chisholm, T., Thompson, L.A., Stanford, J., & Shenkman, E. (2014). Recruiting low income and racially/ethnically diverse adolescents for focus groups. *Maternal and Child Health Journal*, 18(8), 1912-1918. doi: 10.1007/s10995-014-1435-x

Institute for Healthcare Improvement. (2016, September 15). How healthcare can accelerate health equity [Webinar].

Institute for Patient-and Family-Centered Care. (2010). *Tips for recruiting patients and families to serve in advisory roles*. Retrieved from: [http://www.ipfcc.org/resources/Tips\\_For\\_Recruiting.pdf](http://www.ipfcc.org/resources/Tips_For_Recruiting.pdf)





Institute of Medicine [IOM]. (2003). *Unequal Treatment: Confronting racial/ethnic disparities in healthcare*. Retrieved from <http://www.nap.edu/read/12875/chapter/1#ii>

Institute of Medicine [IOM]. (2009). *Toward health equity and patient-centeredness: Integrating health literacy, disparities reduction, and quality improvement: Workshop Summary*. Washington, DC: The National Academies Press.

Institute on Assets and Social Policy [IASP]. (2016, March). *Patient and family advisory councils: Advancing culturally effective patient-centered care*. Retrieved from <https://iasp.brandeis.edu/pdfs/2016/PFAC.pdf>

Kaiser, B.L., Thomas, G.R., & Bowers, B.J. (2017). A case study of engaging hard-to-reach participants in the research process: Community advisors on research design and strategies. *Research in Nursing & Health, 70*, 70-79. doi: 10.1002/nur.21753

Knobf, M.T., Juarez, G., Shiu-Yu, K.L., Sun, V., Sun, Y., & Haozous, E. (2007). Challenges and strategies in recruitment of ethnically diverse populations for cancer nursing research. *Oncology Nursing Forum, 34*(6), 1187-1194. doi: 10.1188/07.ONF.1187-1194

Norris, K.C., Brusuelas, R., Jones, L., Miranda, J., Duru, O.K., & Mangione, C.M. (2007). Partnering with community-based organizations: An academic institution's evolving perspective. *Ethnicity & Disease, 17*, (1 Supp 1), S1-S27.

Peikes, D., O'Malley, A.S., Wilson, C., Crosson, J., Gaddes, R., Natzke, B., Day, T.J., & Ralston, J. (2016). Early experiences engaging patients through patient and family advisory councils. *Journal of Ambulatory Care Management, 39*(4), 316-324. doi: 10.1097/JAC000000000000150

Seeleman, C., Essink-Bot, M.L., Stronks, K., & Ingleby, D. (2015). How should health service organizations respond to diversity? A content analysis of six approaches. *BMC Health Services Research, 15*(510), 1-18. doi: 10.1186/s12913-015-1159-7

Sharma, A.E., Angel, L., & Bui, Q. (2015). Patient advisory councils: Giving patients a seat at the table. *Family Practice Management, 22*(4), 22-27.

Sharma, A.E., Willard-Grace, R., Willis, A., Zieve, O., Dube, K., Parker, C., & Potter, M.B. (2016). How can we talk about patient-centered care without patients at the table? Lesson learned from patient advisory councils. *Journal of the American Board of Family Medicine, 29*(6), 775-784. doi: 10.3122/jabfm.2016.06.150380

Smith, D.G. (2012). Building institutional capacity for diversity and inclusion in academic medicine. *Academic Medicine, 87*, 1511-1515. doi: 10.1097/ACM.0b013e31826d30d5

Weech-Maldonado, R., Elliott, M.N., Adams, J.L., Haviland, A.M., Klein, D.J., Hambarsoomian, K., Edwards, C.,... & Gaillot, S. (2015). Do racial/ethnic disparities in quality and patient experience within Medicare plans generalize across measures and racial/ethnic groups? *Health Services Research, 50*(6), 1829-1849. doi: 10.1111/14756773.12297