

Potential Partners



Partnering with Patients and Families to Strengthen Approaches to the Opioid Epidemic

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Executive Summary

The “opioid epidemic” refers to the serious public health issue stemming from the rapid increase in the use of prescription and non-prescription opioid drugs. To date, there has been a lack of significant and structured partnerships with patients and families in developing national, regional, state, local, and organizational strategies to address the epidemic. As a result, policies and programs are moving forward without contributions from people who are directly impacted.

As an initial step in facilitating meaningful and authentic partnerships with patients and families to address the opioid epidemic, the [Institute for Patient- and Family-Centered Care \(IPFCC\)](#) and [PFCCpartners](#) collaborated to hold a **Patient and Family Advisor (PFA) Summit on the Opioid Epidemic** on June 10, 2018. The PFA Summit is a format developed by PFCCpartners that creates a collaborative space where PFAs; national, state, and local partners; health care providers; researchers; and other stakeholders share and learn from each other.

Nearly 80 participants attended the PFA Summit, over half of whom were **PFAs**—individuals (patients, family members, or members of the community) who draw on their experiences with health care to partner in the development, implementation, and evaluation of policy, programs, and practices. The other participants at the Summit represented national, state, and local **organizations and agencies** that are doing work to address the opioid epidemic and that have the ability to affect change.

The overarching goals of the PFA Summit were to (1) increase participants’ understanding of the opioid epidemic; (2) highlight programs and responses that reflect partnerships with patients and families; and (3) strengthen skills for collaboration moving forward.

“ We have a long history of not asking people what they’re interested in and what they need.”

– PFA Summit Participant

Meaningful Partnerships with Patients and Families in Addressing the Opioid Epidemic



Implementing patient- and family-centered responses to the opioid epidemic involves creating meaningful partnerships with patients and families, particularly individuals who have lived experience with opioid use. Meaningful partnerships are those that move beyond tokenism to include patients and families in ways that enable them to affect change. This involves partnering at all levels of the health care system and beyond, collaborating in all stages of the work, ensuring the inclusion of diverse patient and family perspectives, and acknowledging and addressing biases and stigma.

Examples of Partnerships with Patients and Families to Address the Opioid Epidemic

There are many opportunities for patients, families, and individuals with lived experience to collaborate in shaping and implementing policies and programs related to the opioid epidemic. While work in this area is evolving, several “spotlight examples” provide a starting point for thinking about new strategies and opportunities and reflect existing structures that can be utilized and expanded to accelerate the process of building meaningful partnerships.

These include examples at the national, state, community, and organizational levels related to:

- **Partnerships in Organizational Health Care Quality and Safety Improvement.**

Patients and families can be powerful allies in quality and safety improvement related to the opioid epidemic. One mechanism for developing this partnership is via PFACs—formal groups that meet regularly for active collaboration among PFAs, health care leaders, and clinicians on policy and program decisions. PFACs can provide insights about how to develop approaches to opioid use, misuse, and pain management that best address the needs of patients and families.

- **Community Partnerships in Opioid Prevention and Treatment Programs.**

The U.S. Surgeon General has called community-based recovery support part of the “gold standard” for treating opioid addiction. Individuals with lived experience can partner in efforts to improve treatment and prevention, collaborating with key stakeholders (e.g., law enforcement, health care providers) to design and implement community-based solutions.

- **Peer Support and Education Models of Partnership.** A number of opioid prevention, treatment, and recovery programs incorporate elements of peer support models, drawing on individuals who use their lived experience and specialized training to guide, support, and educate other people seeking recovery. Peer mentors have the opportunity to give back while participating actively in a system that facilitates their continued recovery.

- **Partnerships in Research.** Researchers are beginning to partner with patients and families in developing evidence for approaches to the opioid epidemic, collaborating with them around research design, implementation, and dissemination.

- **Partnerships at the National Level.** At the national level, federal organizations, health care policymakers, and other key stakeholders are partnering with PFAs to inform the development and implementation of policies and practices related to the opioid epidemic.

Recommendations for Promoting Partnerships with PFAs in Addressing the Opioid Epidemic

Developed based on input from participants at the PFA Summit, the following six recommendations are intended to drive progress toward greater partnership with patients and families in addressing the opioid epidemic.

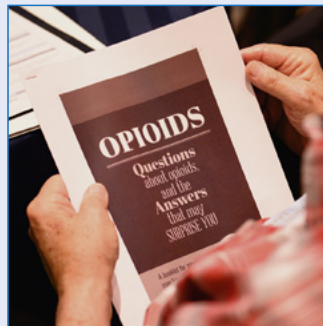
- 1. Build on successful existing partnerships.** Existing PFACs provide a solid foundation from which to build collaborations that address the opioid epidemic.
 - Provide training for current PFAs and PFACs to inform work related to opioid use and misuse.
 - Engage current PFAs and PFACs in opioid-related quality and safety improvement initiatives.
- 2. Prepare patients and families with lived experience for partnership.** Individuals with lived experience offer unique insights for the development of programs and policies that more effectively address the needs of patients and families.
 - Identify and address barriers to participation for individuals with lived experience—i.e., individuals in recovery, individuals who live with acute and chronic pain that is managed with opioids, individuals with active substance use disorder, and families of those affected.
 - Provide training and support to prepare individuals with lived experience for partnership.
 - Develop a national program for individuals to obtain certification as peer support specialists.
- 3. Prepare other stakeholders to foster supportive environments for partnership with patients and families.** Health care leaders, health care providers, researchers, and other national, state, and local organizations play an integral role in creating environments that invite, welcome, and support partnerships with patients and families in opioid-related work.
 - Develop and provide training for clinicians and other stakeholders to build skills for partnering with patients and families.
 - Involve PFAs with lived experience in health professions training.
- 4. Create specific opportunities for partnerships with PFAs in community, state, and national initiatives.** Purposeful partnership at these levels enables individuals with lived experience to shape agendas related to policy, programs, and practice.
 - Designate seats on opioid-related task forces, workgroups, and committees for patients and families.
 - Engage patients and families in developing and implementing legislation and regulations.
 - Partner with patients and families to develop, test, and implement policies for transforming clinical practice.

- 5. Create incentives for partnerships with patients and families.** Partnering with patients and families often requires a culture shift and a willingness to embrace new ways of working. Incentives can accelerate the pace of change.
 - Mandate partnerships with patients and families as part of funding criteria.
 - Engage PFAs in the funding process.
 - Develop compensation guidelines for PFAs.

- 6. Gather and disseminate examples of partnerships with PFAs to share successes and lessons learned.** Capturing and sharing lessons learned helps develop and spread best practices to improve the quality and effectiveness of future partnerships.
 - Capture examples of successful partnerships with patients and families in addressing the opioid epidemic.
 - Develop lessons learned, including from related and intersecting areas.

Conclusion

The PFA Summit demonstrated the power and possibility of partnership, with multiple stakeholders coming together to learn from and share ideas with each other. In seeking to advance progress toward patient- and family-centered approaches to the opioid epidemic, it is imperative to work in partnership with patients and families. Collaborative action is required to advance this work—educating and preparing key stakeholders, explicitly creating opportunities to purposefully include PFAs, and gathering and sharing lessons learned to inform continued and expanded partnerships. While this process may take time, partnerships with patients and families can ultimately accelerate the pace of change.





Introduction

The “opioid epidemic” refers to the serious public health issue stemming from the rapid increase in the use of prescription and non-prescription opioid drugs. As national, state, and local agencies, social service organizations, and health care providers develop strategies and programs to address this epidemic, it is essential to involve patients and families, particularly those with lived experience. However, to date, there is a lack of significant and structured partnerships with patients and families in developing national, regional, state, local, and organizational responses to the epidemic. As a result, policies and programs are moving forward without contributions from people who are directly impacted.

As an initial step in facilitating meaningful and authentic partnerships with patients and families in addressing the opioid epidemic, the [Institute for Patient- and Family-Centered Care \(IPFCC\)](#) and [PFCCpartners](#) collaborated to hold a **Patient and Family Advisor (PFA) Summit on the Opioid Epidemic**. The PFA Summit is a format developed by PFCCpartners that creates a collaborative space where PFAs; national, state, and local partners; health care providers; researchers; and other stakeholders share and learn from each other.

The PFA Summit on the Opioid Epidemic (the PFA Summit) was a day-long, interactive and collaborative event held on June 10, 2018, directly before [IPFCC's 8th International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities](#).

Leadership support for the PFA Summit was provided by [Beaumont Health](#), an eight-hospital health system in Michigan committed to serving as a national exemplar for advancing the practice of patient- and family-centered care (PFCC). Nearly 80 participants attended the PFA Summit, over half of whom were **PFA**s—individuals (patients, family members, or members of the community) who draw on their experiences with health care to partner in the development, implementation, and evaluation of policy, programs, and practices. The other participants at the PFA Summit represented national, state, and local **organizations and agencies** that: (1) are doing work to address the opioid epidemic; (2) can share information and lessons learned to guide partnerships; and (3) have the ability to affect change and facilitate partnerships with patients and families moving forward. (See Appendix 1 for a list of PFA Summit participants.)

The overarching goals of the PFA Summit were to increase participants' understanding of the opioid epidemic, highlight programs and responses that reflect partnerships with patients and families, and strengthen skills for collaboration. For PFAs, an additional goal was to build capacity for existing Patient and Family Advisory Councils (PFACs) to partner in efforts to address the opioid epidemic. The agenda for the PFA Summit included presentations about the current state and impact of the opioid epidemic along with discussions about patient- and family-centered, community, and policy responses. The plan for the day deliberately created space for interaction and discussions, enabling participants to share their knowledge, stories, and experiences while connecting with and empowering one another. (See Appendix 2 for the PFA Summit agenda.)

This White Paper is intended to support progress toward a vision of partnership; one in which all efforts to address the opioid epidemic—e.g., improve pain management, reduce inappropriate use of opioids, enhance peer support, and develop recovery support programs—elicit and respond to the needs and priorities of patients and families. Likewise, it is intended to facilitate collaboration with patients and families in developing, implementing, evaluating, and disseminating solutions. This White Paper summarizes the rich discussion from the PFA Summit, while also extending its scope.

Specifically, the White Paper:

- Discusses what it means to have meaningful partnerships with patients and families in addressing the opioid epidemic in the United States and beyond.
- Describes current efforts to address opioid use and misuse that provide examples of partnerships with patients and families at the national, state, community, and organizational levels.
- Provides recommendations designed to drive progress toward greater partnership.

“ We have a long history of not asking people what they’re interested in and what they need.”

– PFA Summit Participant

Meaningful Partnerships with Patients and Families in Addressing the Opioid Epidemic

Patient- and family-centered care (PFCC) is an approach to health care that emphasizes collaboration with people of all ages, with all conditions, at all levels of care, and in all care settings. Implementing patient- and family-centered responses to the opioid epidemic involves creating meaningful partnerships with patients and families, particularly individuals who have lived experience with opioid use. When patients and family members have structured roles within health care settings, collaborating with health care professionals in improvement and transformation, we refer to them as patient and family advisors, or PFAs.¹ PFAs can make significant contributions by:

- **Informing a greater understanding of the opioid epidemic.** PFAs can help shed light on patients’ and families’ perspectives related to opioid use, prevention, and treatment. They can also inform a greater understanding of the complexities of opioid use disorder (OUD) on an individual, community, and population level. This includes sharing experiences and perspectives about the relationship between OUD and intersecting issues such as poverty, physical and psychological traumas, mental health, and criminal justice.
- **Identifying barriers to prevention and treatment.** Developing effective programs and approaches for addressing the opioid epidemic requires understanding the reality of patients’ and families’ lives. PFAs can illuminate real and perceived barriers to prevention and treatment experienced by patients and families that otherwise may not be apparent. For example, patients may wish to pursue non-pharmacological approaches to pain management but experience challenges such as the inability to take time off from work to attend physical therapy sessions or a lack of health insurance coverage for acupuncture or other evidence-based complementary and alternative health approaches.
- **Helping to develop solutions and approaches that respond to patient and family needs.** PFAs can help develop materials, processes, and approaches that are responsive to patient and family perspectives, increasing the likelihood of relevance, uptake, and effectiveness. They can also help identify cross-cutting strategies that promote holistic approaches to care and help ensure that potential messages and interventions are culturally and linguistically appropriate.

¹ Throughout this White Paper the term PFA is used broadly to include individuals with lived experience, as well as patients and families who do not have direct experience with opioid use but who have previous experience as PFAs.

Characteristics of Meaningful Partnerships

Meaningful partnerships are those that move beyond tokenism to include patients and families in ways that enable them to affect change. The characteristics of “meaningful partnerships” in addressing the opioid epidemic include:

“We need to move partnership with patients and families and co-design further upstream.”

— Libby Hoy,

Founder and CEO of
PFCCpartners

Partnerships at all levels and in all stages of work

Partnerships with patients and families need to occur at all levels of the health care system and beyond, affecting change related to direct care interactions; policies and practices within health care organizations and systems; education of clinicians and staff; research and evaluation; community programs and agencies; incarceration policies and reentry programs; and state, regional, and national opioid initiatives. Meaningful partnerships require collaborating with PFAs in all stages of the work, with purposeful inclusion from the beginning. Additionally, participants at the PFA Summit noted the importance of being willing to make changes based on PFA input at all stages—from planning to implementation to evaluation of programs, services, and support.

Inclusion of diverse patient and family perspectives

Identifying solutions to the opioid epidemic requires inviting and supporting participation from patients and families with diverse perspectives and backgrounds. This means partnering with individuals directly and indirectly affected by the opioid epidemic, including individuals with OUD; individuals in recovery; individuals who are living with episodes of acute and chronic pain who may rely on opioids as part of their pain management strategy (e.g., people with sickle cell disease and other hematologic disorders, neuropathy, blood cancers); and families who have been impacted by a loved one’s opioid use. Attention to diversity requires reaching out to individuals and groups whose voices are traditionally under-represented in decision-making about health care policies and programs, and, as needed, providing support to facilitate their participation.

“We need to build an army of diversity with shared interests.”

– PFA Summit
Participant

Tamela Milan-Alexander, MPPA, MCH, Partnership and Outreach Worker at Access Westside Healthy Start Community Action Network in Chicago, shared her personal and moving story of addiction and recovery at the IPFCC 8th International Conference, A Mother's Story: Her Journey in Becoming a Community Advocate.



Watch the presentation.

Acknowledging and addressing biases and stigma

“We all have biases. We tend to think that a middle-aged, married, professional woman who has back surgery and becomes addicted to opioids has an ‘acceptable’ opioid use disorder while others do not.”

— PFA Summit Participant

Stigma plays an unseen but highly consequential role in the opioid epidemic. For individuals and families affected by OUD, stigma can diminish feelings of self-worth, increase isolation, and decrease engagement in treatment and care. Recognizing and confronting stigma and biases—both implicit and explicit—is an important facilitator of interactions and conversations with patients and families in which collaboration feels safe and welcome. One concrete way to address biases is to ensure that the language used in discussing the opioid epidemic is person-driven, strengths-based, precise, and descriptive rather than judgmental (see Exhibit 1).

Sarah Wakeman, MD, Medical Director for the Mass General Hospital Substance Use Disorder Initiative, gave a presentation at the IPFCC 8th International Conference that touched on the role stigma plays in addressing the opioid crisis: Science, Story, and Stigma: Understanding and Effectively Responding to the Crisis of Opioid Overdose and Addiction.



Watch the presentation.



Changing the conversation around opioid use and misuse: The importance of language

INSTEAD OF...	USE...	BECAUSE...
Addict, drug abuser, junkie, drug seeker, pill seeker	Person with a substance use disorder	Person-first language is non-judgmental and separates the individual from their disease, rather than defining them based on their medical condition.
Former addict	Person in recovery Person in long-term recovery	
Drug abuse	Drug misuse Harmful use	"Abuse" implies that the individual is an abuser and lessens the emphasis on substance use disorders as a medical condition.
Drug habit	Substance use disorder	"Habit" implies that drug use can be overcome through willpower.
Being "clean" or "dirty"	Being abstinent, being sober, not using, testing positive or negative for substance use	Being "clean" suggests that the alternative is "dirtiness."
Drug-addicted babies	Babies born with prenatal substance exposure, Newborn Opioid Withdrawal	Addiction and dependence are not the same; babies are not addicted but may have withdrawal symptoms based on exposure.
Drug binge	Heavy substance use over a short time	"Binge" has negative connotations and is an imprecise description.
Opioid replacement, methadone maintenance	Medication Assisted Treatment, Opioid Agonist Treatment	"Replacement" frames medication as substituting legal opioid use for illicit opioid use, instead of including it as a critical part of treatment and preventing relapse.



Examples of Partnerships with Patients and Families to Address the Opioid Epidemic

There are many opportunities for patients, families, and individuals with lived experience to collaborate in shaping and implementing policies and programs related to the opioid epidemic – including improving pain management, reducing inappropriate prescribing and use of opioids, contributing to quality and safety improvements around opioid use, and developing programs to support individuals in recovery. While work in this area is evolving, there are existing “spotlight examples” of partnerships. These examples provide a starting point for thinking about new strategies and opportunities and also reflect existing structures that can be utilized and expanded to accelerate the process of building meaningful partnerships.

Partnerships in Organizational Health Care Quality and Safety Improvement



Patients and families can be powerful allies in quality and safety improvement related to the opioid epidemic. One mechanism for developing this partnership is via PFACs—formal groups that meet regularly for active collaboration among PFAs, health care leaders, and clinicians on policy and program decisions. Partnering with new or existing PFACs can provide insights about how to develop approaches to opioid use, misuse, and pain management that best address the needs of patients and families.

A PFAC to Improve Pain Management: AMITA Health St. Alexius Medical Center

At St. Alexius Medical Center in Illinois, pain management was identified as a top priority for improvement.² Recognizing the need to understand patient perspectives and priorities, the hospital undertook a one-year collaborative process that involved forming a PFAC to address pain management. The PFAC—which consisted of PFAs, a multidisciplinary nursing team, and administrative leaders—gathered the patient perspective on what it meant for care providers to “help with pain” and used the data to develop strategies for a pilot. Components of the pilot included redesigning the pain management nursing assessment form, developing a menu of non-pharmaceutical pain control and comfort options, partnering with hospital volunteers to offer items on the menu through a hospital “comfort cart,” and developing a pre-surgery guidebook to educate orthopedic patients about what to expect related to their pain and pain management during and after the hospital stay. Initial goals were to increase HCAHPS ratings related to pain management from a baseline of 69.8% to 78.3% or higher, and to increase the HCAHPS overall hospital rating from a baseline of 78.3% to 84.6%. While St. Alexius hoped to meet these goals by the end of 12 months, they surpassed them within three months, achieving an HCAHPS pain management rating of 78.9% and overall HCAHPS rating of 90.3%.

Partnering with PFAs on Patient Education: Beaumont Health

In July 2018, new state laws took effect in Michigan that prohibit physicians from writing prescriptions for more than a seven-day supply of opioid medications for patients with acute pain. Recognizing that patients and families might have questions about the new prescribing laws, Beaumont Health—which provides health care in Southeast Michigan through eight hospitals and 187 health centers—partnered with PFAs to develop a letter for patients that described the new legislation. Based on input from PFAs, the letter contains supportive language and positive messaging (e.g., “we are here to help,” “your safety is our number one priority”) while also clearly communicating elements of the law related to prescribing requirements and patient education. The letter also refers patients and families to a [website](#) that Beaumont Health established to provide patients with resources and strategies for coping with and self-managing pain.

Partnering with a PFAC to Inform Statewide Pain Management Education: MHA Keystone Center

The Michigan Health and Hospital Association (MHA) Keystone Center has a PFAC that helps guide patient and family engagement-related work on a statewide level. Recognizing opioid misuse as a significant issue, MHA worked with its PFAC to change and improve pain management practices across the state. The PFAC identified several critical issues: a lack of appropriate education for patients about pain management, insufficient expectation-management regarding pain as a normal part of the healing process, and a lack of knowledge about how to safely dispose of leftover pain medication. MHA worked with its PFAC and a team of experts, including an anesthesiologist, pain management specialist, surgeon, and health literacy expert, to develop a resource titled “[Your Guide to Controlling and Managing Pain After Surgery](#).” Released in 2013, the Guide includes tools for patients to document their pain management plan; tools for tracking pain, medications, and side effects; and information about how patients can participate in their care and why it is important to do so. MHA also worked with its PFAC on a public awareness campaign related to opioid use and pain management. The campaign included a Twitter chat that generated over 1.5 million impressions and included participation from the Michigan State Medical Society, state police, physicians’ groups, and patients and families. Finally, learning from the PFAC that patients did not understand procedures for safe disposal of leftover pain medications, MHA worked with the Michigan Pharmacists Association and the Michigan Department of Environmental Quality to develop an education campaign and interactive map of “take back” locations across the state.

Community Partnerships in Opioid Prevention and Treatment Programs

The U.S. Surgeon General’s spotlight report on opioids notes that community-based recovery support is part of the “gold standard” for treating opioid addiction.³ Individuals with lived experience can partner in efforts to improve treatment and prevention, collaborating with key stakeholders (e.g., law enforcement, health care providers) to design and implement community-based solutions.

A Comprehensive Approach to Addressing Opioid Use in North Carolina: Guilford County Solution to the Opioid Problem (GCSTOP)

[Guilford County Solution to the Opioid Problem \(GCSTOP\)](#) was established through the Center for Housing and Community Studies at the University of North Carolina at Greensboro (UNCG) in recognition of the significant impact that opioids have in Guilford County, North Carolina. Launched in 2018, the goals of the program are to: (1) reduce the incidence of deaths due to opioid overdose in Guilford County by 20%; (2) make in-person contacts with all survivors of opioid overdose within 72 hours of overdose reversal; (3) provide naloxone education and administration training to all contacted opioid overdose survivors; (4) give brief substance use counseling to all contacted opioid overdose survivors; (5) provide follow-up harm reduction and recovery-oriented care and support to survivors of opioid overdose; and (6) develop a syringe exchange program for intravenous opioid users.

“We meet people where they are and build relationships. Then they realize we’re safe. We’re there to spread love, not hurt them.”

— GCSTOP Navigator

Within 72 hours of being revived by EMS, individuals who have experienced an overdose receive a visit from an addiction specialist field worker (GCSTOP Navigator). During the visit, the Navigator screens for risk of repeat overdose, assesses current substance use disorder, discusses treatment options, provides education about harm reduction, and distributes and provides training on the use of naloxone. Within six months, there were 73,600 syringes and 468 doses of Narcan distributed through the program; 141 referrals to treatment and linkages to care; and 65 reversals. GCSTOP also aims to reduce stigma and engage the community via community education events. GCSTOP has hired an individual who is in long-term recovery as navigator and case manager and several Master of Social Work (MSW) and Bachelor of Social Work (BSW) interns with lived experience, including their syringe exchange coordinator.

³U.S. Department of Health and Human Services (HHS), Office of the Surgeon General. (2018, September). Facing addiction in America: The Surgeon General’s spotlight on opioids. Washington, DC: HHS. Retrieved from https://addiction.surgeongeneral.gov/sites/default/files/Spotlight-on-Opioids_09192018.pdf

Training Community Health Workers on Opioid Prevention and Intervention: Massachusetts

Community Health Workers (CHWs) are frontline public health workers who are trusted members of the community and/or have a close understanding of the communities they serve. Their role is to facilitate access to services and improve the quality and cultural competence of service delivery by providing a link between health and social services and the community. In Central Massachusetts, CHWs have the option to take a free, 80-hour certificate course as part of efforts to integrate CHWs into state and local strategies to address the opioid epidemic. During training, CHWs learn about and share their knowledge of the opioid epidemic, develop an understanding of options for opioid prevention and intervention, discuss cultural responsiveness related to the opioid epidemic, receive education about healthy behavior change, and learn how to facilitate capacity-building in the community. In this way, CHWs are helping to create bridges between affected individuals, communities, and local and state efforts.



A Collaborative Approach to the Addiction Epidemic: Stop the Addiction Fatality Epidemic (S.A.F.E. Project)

[S.A.F.E. Project](#) was founded in November 2017 by Retired Admiral James Winnefeld and Mary Winnefeld after their son's death from an opioid overdose. S.A.F.E. Project advocates for a collaborative, multi-pronged approach to ending the opioid epidemic. This comprehensive approach includes six "lines of operation":

- **Public awareness:** Raise awareness of the disease of substance use disorder—including its causes, risks, impact, and solutions—to reduce stigma and gain public support for efforts to reverse the epidemic.
- **Full-spectrum prevention:** Help reduce the number of people impacted by substance use disorder through targeted efforts to educate populations regarding the hazards of, and ways to avoid, opioid abuse.
- **Prescription medicine:** Help reduce the number of people affected by substance use disorder through targeted efforts to inform patients, and families and influence pharmacists, prescribers about the hazards of prescription drug misuse.
- **Law enforcement and medical response:** Enhance law enforcement, criminal justice, and medical first responder efforts to decrease the supply of illicit drugs, prevent fatal overdoses, and facilitate transition to treatment at every opportunity.
- **Treatment and recovery:** Assist those seeking treatment and recovery by contributing to efforts that increase the quality and availability of care and providing rapid, tailored support to individuals, families, and communities.
- **Family outreach and support:** Provide meaningful advice and a shared community for friends and family members who are coping with a loved one's substance use disorder, treatment, transition, or recovery.

The S.A.F.E. Project has a specific focus on campuses and communities. S.A.F.E. Campuses is designed to ensure access to effective support services through the creation of collegiate recovery programs (CRPs), and hosting Campus Recovery Leadership Academy convenings for students. The S.A.F.E. Project Community Playbook aims to help local communities identify and gather key stakeholders; evaluate the community's assets and resources related to prevention and treatment; map existing resources to the S.A.F.E. Project's six lines of operation; and build a customized Playbook for the community to address areas of greatest need.

Peer Support and Education Models of Partnership

A number of opioid prevention, treatment, and recovery programs incorporate elements of peer support models, drawing on the capacities of individuals who use their lived experience and specialized training to guide, support, and educate people seeking recovery. As evidence-based practice, peer support programs offer non-judgmental, practical information and support and reduce isolation for individuals with substance use disorder while also connecting them to resources in the community. In turn, peer mentors have the opportunity to give back and participate actively in a system that facilitates their continued recovery.

Providing Support to Individuals Seeking Treatment: Peer Recovery Specialists at Dee's Place

Dee's Place is a peer-run support center that serves people in East Baltimore, Maryland who are seeking help with alcohol and other substances. For the past 18 years, Dee's Place has provided services including referring individuals to drug treatment programs, helping them develop wellness and recovery plans, and connecting them to a variety of services in the community, including housing and job training. At Dee's Place, which is open seven days a week for nearly 24 hours a day, peer support is provided via group meetings and one-on-one counseling by staff and trained volunteers who have personal experience with alcohol and substance use. These individuals have been certified through Maryland's Certified Peer Recovery Specialist program, which offers State certification for individuals who provide direct peer-to-peer support services to others who have mental health, substance use, or co-occurring disorders. Certified Peer Recovery Specialists must demonstrate knowledge and skills in key areas relating to advocacy, mentoring, education, and recovery support.

Empowering Individuals and Communities to Address Narcotic Addiction: Families Against Narcotics

Started in 2007, Families Against Narcotics (FAN) is a grass roots organization in Michigan that aims to raise awareness about narcotic use; provide education to youth, adults, parents, school personnel, law enforcement, judges, and health care professionals; and support those affected by narcotic addiction. Currently, the organization has 20 chapters in Michigan and, in 2017, launched its first out-of-state chapter in Madison, North Carolina. A key component of FAN's model involves fostering relationships within the recovery community and working with individuals whose lives have been touched by narcotic addiction. Through FAN's "Real People Sharing Real Stories," parents affected by addiction and young people in recovery share their stories in schools to raise awareness and provide education to the community.

FAN's "Hope Not Handcuffs" program, which was started by a mother who experienced her daughter's addiction, creates partnerships with law enforcement and community organizations to help individuals seeking treatment. Through the program, individuals struggling with drug addiction can go to participating police departments to ask for help. FAN will then dispatch one of over 200 volunteer "Angels"—the majority of whom have lived experience with addiction—to assist the individual in finding treatment options while also providing compassionate support. When people are discharged from treatment, FAN pairs them with a trained peer recovery coach for as long as needed. As FAN works to create a strong recovery support network, they also are exploring adding family recovery coaches in the future.

Providing Support to Pregnant Women Who Are At-Risk or Using: MOMS Programs

Two programs, one in Ohio and one in Oregon, provide peer support to pregnant women who are at risk for substance use or currently using opioids. The Maternal Opiate Medical Support (MOMS) Program in Lucas County, Ohio provides both treatment and support to pregnant women who are using opioids. Funded by a grant from the Ohio Department of Mental Health and Addiction Services, the goals of the program include improving maternal and fetal health outcomes (e.g., reducing the number of children born with Neonatal Abstinence Syndrome (NAS), reducing the length of hospital stays, and increasing birth weights), improving family stability, and reducing costs of NAS. The program combines medication-assisted treatment (MAT) with peer support. In the peer support component, women receive support from MOMS program staff and each other, and meet weekly as a group to discuss education and resources. The program also provides an opportunity for women to seek support related to myriad aspects of pregnancy and parenting (e.g., nutrition, lactation counseling).

In Oregon, a separate MOMS program run by the WVP Health Authority (an association with over 500 members who practice primary and secondary care) uses a peer mentoring model to provide support to pregnant women who are at risk for substance use. The Oregon MOMS program also aims to address multiple factors that contribute more broadly to family health, including housing, food, employment, and criminal justice issues. Upon referral to the MOMS program, pregnant women have a scheduled home visit with a peer mentor who provides information about the program and handles consent and enrollment. The peer mentor works with the woman throughout her pregnancy—and beyond, if needed—connecting her with needed services (e.g., housing, food, employment) and providing support. When women "graduate" from the program, they are encouraged to remain active, sharing their experiences and success to create a strong support network.

Incarceration program

The Mission of Contra Costa Health Services (CCHS) in Northern California is to improve the health of all citizens in the county, especially those most vulnerable. Within the CCHS Behavioral Health Division, the Office of Consumer Empowerment employs peer workers with lived experience with mental health treatment or substance use disorder to lead a variety of programs that promote recovery and self-empowerment and reduce stigma. These programs include:

- Service Provider Individualized Recovery Intensive Training (SPIRIT), with peer and family providers
- SPIRIT Vocational Program
- Wellness Recovery Action Plan (WRAP), a self-designed prevention and wellness process offered in a variety of locations, including detention facilities, forensic mental health, and inpatient facilities for alcohol and other drug treatment services
- Social inclusion
- Wellness and Recovery Education for Acceptance, Choice, and Hope (WREACH) Speakers Bureau
- Photovoice Empowerment Project

To address the needs of individuals who have been incarcerated, many of whom have substance use disorder, the CCHS Office of Health Disparities has a program called REMEDY Re-entry Health Conductors Program. REMEDY is designed to address the health disparities and social inequities facing the returning citizen. The 8-week curriculum addresses barriers that returning citizens face regarding health, employment, housing, and full integration into their communities. Graduates of the program are invited to continue participating in the REMEDY network to provide peer leadership, advocacy, and mentoring training to support current participants.



Partnerships in Research

Historically, patients and families have been the subjects of health care research, as opposed to collaborators. That is changing, as researchers are beginning to partner with patients and families in research design, implementation, and dissemination, including in developing evidence for approaches to the opioid epidemic. The Patient-Centered Outcomes Research Institute (PCORI) has played a key role in the evolution of these partnerships, creating funding guidelines that require researchers to engage patients and families as collaborators and essential members of research teams.

Trial of Patient-Centered Care for OUD in Federally Qualified Healthcare Centers and Specialty Care Settings

Funded by PCORI, this study is investigating a more patient-centered approach to OUD by comparing treatment that is integrated into primary care with the typical approach of referring people to off-site treatment centers. The goal is to reduce burden for low-income participants who are treated at federally qualified healthcare centers (FQHCs) by integrating a collaborative team approach within primary care, providing individualized OUD treatment at the FQHC on a flexible schedule. The treatment includes a menu of evidence-based practices, including medication-assisted treatment, cognitive-behavioral relapse prevention, contingency management, and peer support. In addition to providing a more patient-centered approach to treatment, the research team is also working collaboratively with patients to plan and conduct the study. The approach includes a patient co-investigator along with a Community Advisory Board whose members are patients in recovery; the Board meets monthly to provide guidance to researchers.

Comparative Effectiveness of Cognitive Behavioral Therapy and Chronic Pain Self-Management Within the Context of Opioid Reduction

This study, also funded by PCORI, aims to compare two types of patient-centered pain management classes—an eight-week group cognitive behavioral therapy program and a six-week peer-led chronic pain self-management program. Investigators developed the study based on input from patient stakeholders, and also created a Study Advisory Board and Patient Rapid Response mechanism to obtain input and feedback from a larger, more diverse group of patient stakeholders. Input from patients was used to inform the outcomes that will be tracked (e.g., pain intensity and interference, opioid use, anxiety and depression, fatigue, and medication side effects).

Partnerships at the National Level

The Centers for Medicare and Medicaid Services (CMS) describes patients and their families as “essential partners in the effort to improve the quality and safety of care.”⁴ At the national level, federal organizations, health care policymakers, and other key stakeholders can partner with PFAs to inform the development and implementation of policies and practices related to the opioid epidemic.

U.S. Food and Drug Administration (FDA) Patient-Focused Drug Development for Chronic Pain

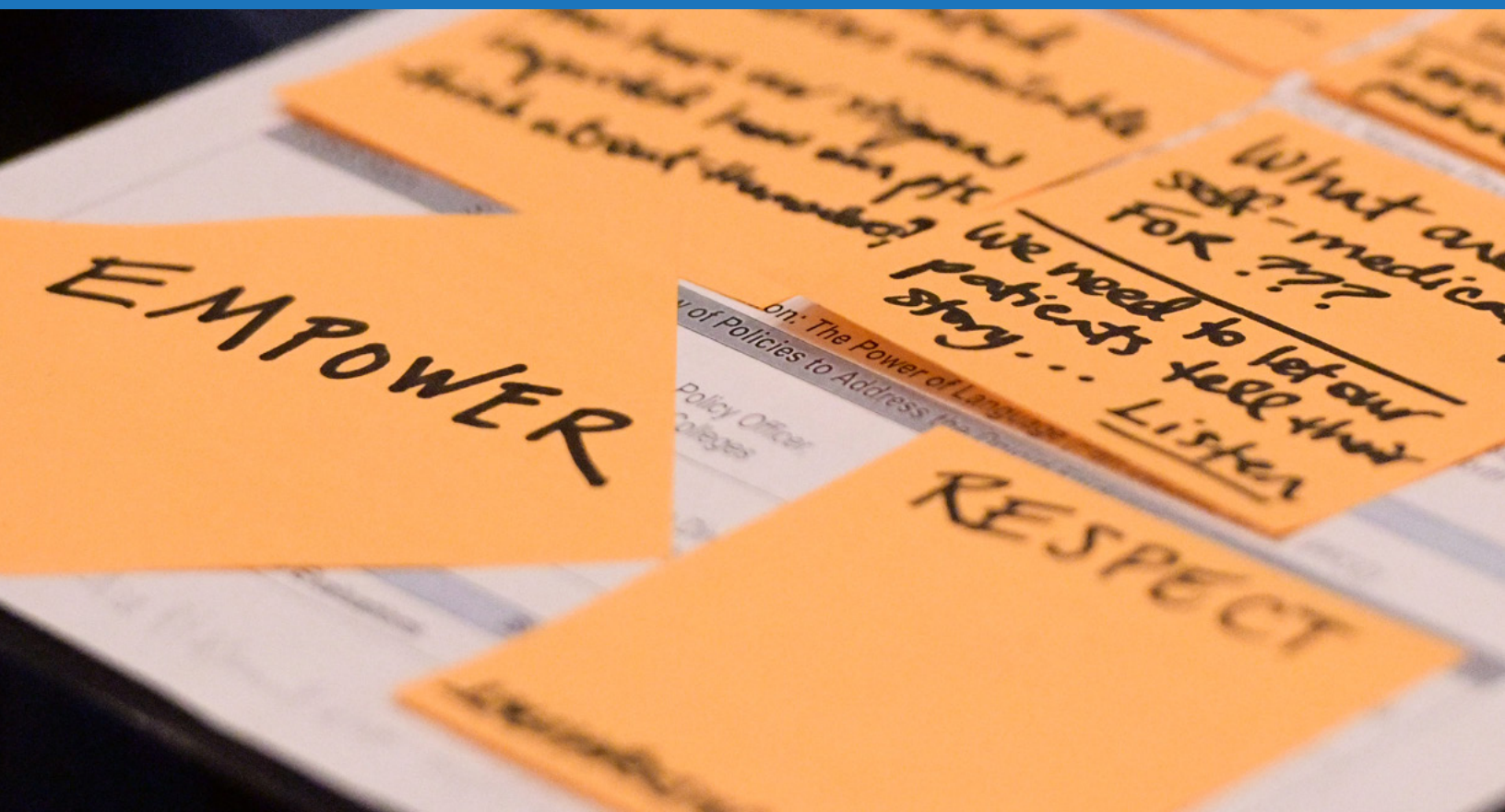
Patient-focused drug development (PFDD) meetings provide an opportunity for key stakeholders (e.g., FDA staff, researchers, drug developers, health care providers, patient advocates) to hear directly from patients, obtaining their perspectives on specific diseases and treatments. In July 2018, the FDA convened a PFDD meeting to hear patients’ views on chronic pain, treatment approaches, and challenges or barriers to accessing treatments for chronic pain. The public announcement for the meeting noted the FDA’s desire to hear from “patients who experience chronic pain that is managed with analgesic medications such as opioids.” During the day-long meeting, patients were asked to provide feedback on two main topics through panels and group discussions: “symptoms and daily impacts of chronic pain that matter most to patients,” and “patients’ perspectives on current approaches to chronic pain.”

“When we bring just clinicians together, we tend to focus on how we develop and implement policies. Having patients at the table helped us think very critically about what the impact is on patients and families...It helped elevate awareness about what is really happening with patient interactions with their providers in the health care system.”

– NQF Representative

National Quality Forum’s National Quality Partnership Playbook™ for Opioid Stewardship

In September 2017, the National Quality Forum (NQF) convened the National Quality Partnership (NQP) Opioid Stewardship Action Team, bringing together over 40 organizations, including federal agencies, health care professionals, specialty societies, and patient and family partners. The goal was to address potential gaps in quality, identify areas of improvement and opportunity in addressing the opioid epidemic, and discuss specific strategies and tactics for helping clinicians manage patients’ pain while reducing the risk of OUD. As a result of the Action Team, NQF released the NQP Playbook™ for Opioid Stewardship. Intended as a resource for health care organizations and clinicians, the Playbook contains concrete strategies and implementation examples for addressing the opioid epidemic and emphasizes seven key fundamentals of action, one of which is patient and family caregiver education and engagement. The Playbook encourages clinicians to engage patients and families in discussions of the risks and benefits of pain management options, provide both real-time and ongoing education, work with patients to set realistic pain management goals, and ensure that patients’ pain management plans are individualized to their needs. The Playbook encourages broader partnerships in addressing the opioid epidemic, including implementation examples that encourage health care providers to engage PFACs in opioid work.



Recommendations for Promoting Partnerships with PFAs in Addressing the Opioid Epidemic

Discussions at the PFA Summit focused on strengthening the capacity to create partnerships among PFAs, clinicians, staff, leaders, and other stakeholders to guide change and improvement in addressing the opioid epidemic. Based on the rich discussion and input from participants, the following recommendations are intended to mobilize progress toward greater partnership with PFAs in addressing the opioid epidemic.

In addition, PFA Summit participants expressed the critical need for all partners to work together to build a patient- and family-centered, coordinated approach to OUD education, prevention, treatment, and recovery. Participants' description of this coordinated approach is summarized in Appendix 3.

At the IPFCC 8th International Conference, Leana Wen, MD, former Commissioner of Health, Baltimore City Health Department, discussed coordinated approaches to address the opioid epidemic in Baltimore, MD: Partnerships for Promoting Health Equity and Reducing Disparities.



[Watch the presentation.](#)

Recommendation 1: Build on Successful Existing Partnerships

In addition to serving on PFACs, PFAs in many organizations are embedded in quality and safety committees, serve as faculty members for the education and training of health care professionals, and participate as co-investigators in research projects. These existing structures provide a solid foundation from which to build collaborations that address the opioid epidemic.

Specific opportunities include:

- **Provide training for current PFAs and PFACs to inform work related to opioid use and misuse.** While many people are aware that OUD is a growing problem, providing existing PFAs with thoughtful preparation and training can expand their capacity for partnership and help them engage more effectively in developing solutions. This includes sharing information about the magnitude of the opioid epidemic; efforts at the national, state, and local level to address opioid use and misuse; and current opioid-related quality and safety improvement initiatives.
- **Engage current PFAs and PFACs in opioid-related quality and safety improvement initiatives.** Organizations that currently have PFACs can involve them in opioid-related work and invite PFAs to serve on key committees. PFAs can help gather patient and family perspectives on pain management, identify gaps in current pain management education and practice, co-develop materials and messaging to ensure effective communication about opioid use, and assist in planning and evaluating non-pharmacological approaches to pain management.



Recommendation 2: Prepare Patients and Families with Lived Experience for Partnership

A significant shortcoming in current approaches to addressing the opioid epidemic is the frequent failure to include individuals with lived experience—i.e., individuals in recovery, individuals who live with acute and chronic pain that is managed with opioids, individuals with active substance use disorder, and families of those affected. (See Appendix 4 for additional information about partnering with individuals who have active substance use disorder). These individuals offer unique insights for the development of programs and policies that more effectively address the needs of patients and families. In turn, participation in this work can give individuals with lived experience a sense of purpose, pride, and accomplishment.

“There are very real barriers to patients being able to participate in this work. This isn’t their day job.”

— PFA Summit Participant

Specific opportunities include:

- **Identify and address barriers to participation for individuals with lived experience.** Working to actively dismantle barriers facilitates the inclusion of diverse populations that are representative of the individuals affected by the opioid epidemic. Policies and practices that support participation include: reimbursement of travel and child care expenses, stipends or honoraria, virtual participation at meetings, options for contributing that do not require background checks, and relationship- and trust-building activities through community outreach.
- **Provide training and support to prepare individuals with lived experience for partnership.** In addition to helping individuals with lived experience learn how to partner in improvement and transformational change efforts, training can increase confidence, knowledge, and skills related to leadership, effective advocacy, public speaking, and the sharing of personal stories. Current PFAs can contribute by serving as peer mentors to new PFAs.
- **Develop a national program for individuals to obtain certification as peer support specialists.** As peer support specialists, individuals with lived experience can help individuals with OUD identify treatment options, navigate systems of care, and engage in the recovery process. While opioid-specific peer support certification programs exist, the standards associated with certification vary greatly. In the behavioral health area, Mental Health America addressed this issue through creation of a National Certified Peer Specialist certification. Developing similar certification for peer support specialists for OUD could set standards for competencies, facilitate the inclusion of individuals with lived experience, and encourage the expansion of peer support in different payment models and care settings.

Recommendation 3: Prepare Other Stakeholders to Foster Supportive Environments for Partnership with Patients and Families



Developing patient- and family-centered responses to the opioid epidemic requires partnership within and between multiple systems and stakeholders. (See Appendix 5 for a list of potential stakeholders developed by participants at the PFA Summit). Health care leaders, health care providers, researchers, and other national, state, and local organizations play an integral role in creating environments that invite, welcome, and support partnerships with patients and families in opioid-related work. However, these key stakeholders often receive little, if any, training to help them work in meaningful ways with patients and families.

Specific opportunities include:

- **Develop and provide training to build stakeholder skills for partnering with patients and families.** PFAs can assist in developing and delivering toolkits and curriculum modules that provide training for clinicians and non-clinical stakeholders (e.g., front-line staff, faith groups, schools and universities, housing authorities, and other community-based organizations). Potential topics for training include how to invite and engage individuals with lived experience as members of projects and teams; structure partnership opportunities to facilitate meaningful interactions; and sustain partnerships over time. Bringing together stakeholders from multiple disciplines for training can help build on complementary expertise and experience.
- **Involve PFAs with lived experience in health professions training.** As medical schools and other health professions training programs work to address the opioid epidemic, a key task involves translating academic knowledge into real-world practice and change. PFAs, particularly those with lived experience, can play an important role in educating leaders, health care professionals, students and trainees, community outreach workers, and others in the health professions workforce, particularly key specialties such as addiction medicine, addiction psychiatry, and pain medicine. PFAs can help develop curricula, serve as faculty and lecturers, contribute to experiential learning, and participate in skill checks related to the development of interpersonal techniques. Opportunities for partnership extend along the educational continuum—from medical school to fellowship programs to continuing medical education.

Recommendation 4: Create Specific Opportunities for Partnerships with PFAs in Community, State, and National Opioid Initiatives

At community, state, and national levels, various quality and safety initiatives that aim to address the opioid epidemic routinely include representatives from government agencies, health systems, provider groups, payers, industry, and academic institutions on workgroups and task forces. Patients and families are infrequently included. However, purposeful partnership at this level enables those with lived experience to shape agendas related to policy, programs, and practice. Moreover, these opportunities can help PFAs develop skills for continued leadership and engagement.

Specific opportunities include:

- **Designate seats on opioid-related task forces, workgroups, and committees for patients and families.** Whenever possible, these groups should invite full membership from patients and families, including individuals with lived experience, and provide compensation for participation. This includes patient and family participation in state- and regional-level task forces; health care system committees; and workgroups convened by professional societies, government agencies, and others. Individuals who currently serve as PFAs — particularly those with more extensive experience — are excellent candidates for such roles.
- **Engage patients and families in developing and implementing legislation and regulations.** Patients and families can contribute in meaningful ways to developing and enacting legislation and regulations to address the opioid epidemic. As an example of an opportunity for patient and family partnership, Massachusetts recently passed an [opioid bill](#) that requires health insurers to cover a full array of non-pharmacological pain treatments. Before this provision goes into effect, it will be studied to determine which therapies should be covered. This represents an opportunity to engage patients and families to ensure that final rules consider and respond to their priorities. As another example, legislation has been proposed to address treatment gaps through health care workforce training, including funding additional training programs in addiction medicine and addiction psychiatry. If this or other similar legislation moves forward, a component could involve mandating that patients and families with lived experience be an integral part of developing, implementing, and evaluating curricula for these training programs.
- **Partner with patients and families to develop, test, and implement policies for transforming clinical practice.** At regional, state, and national levels, there are multiple initiatives related to medication management and opioid safety that represent opportunities for partnership with patients and families. For example, CMS's [Campaign for Meds Management \(CMM\)](#) engages patients, caregivers, health care providers, insurers, and other public and private partners to identify and share promising medication management strategies and resources.

Recommendation 5: Create Incentives for Partnerships with Patients and Families



Partnering with patients and families often requires a culture shift and a willingness to embrace new ways of working. Incentives can accelerate the pace of change. RIZE Massachusetts—an independent nonprofit foundation working to end the opioid epidemic in the state—recently awarded grants to four organizations to support programs and approaches to treatment for OUD. Grantees were asked to implement approaches around five key criteria, one of which was “involving those with lived experience in planning, implementation, and feedback.”

Specific opportunities include:

- **Mandate partnerships with patients and families as part of funding criteria.** Requests for proposals (RFPs) and grant announcements from public and private funders could require the engagement of patients and families in projects designed to address OUD, ensuring that individuals with lived experience are meaningfully involved in all phases of the project work. Funders could also develop guidelines and FAQs to educate applicants about partnering with patients and families in meaningful ways.
- **Engage PFAs in the funding process.** Moreover, funders themselves could partner with PFAs in developing funding announcements, outlining award criteria, and participating in the review process—e.g., having individuals with lived experience serve as members of grant review teams.
- **Develop compensation guidelines for PFAs.** A significant barrier to partnering with patients and families is the assumption—by funders and others—that PFAs will contribute as volunteers. Funders could institute requirements for fair compensation for individuals with lived experience for their participation in efforts to address the opioid epidemic. Compensating PFAs for their time demonstrates a commitment to partnership and signals appreciation for their expertise and value.

Recommendation 6: Gather and Disseminate Examples of Partnerships with PFAs to Share Successes and Lessons Learned

Capturing and sharing lessons learned helps develop and spread best practices to improve the quality and effectiveness of future partnerships. It can also help other individuals and organizations identify potential alliances and opportunities for partnership that they may not have previously considered.

Specific opportunities include:

- **Capture examples of partnership and success.** Documenting examples of meaningful partnerships can highlight opportunities for other stakeholders to engage in similar work. Capturing information about programs that are working—including implementation details—allows others to replicate and build on successes. These success stories can also convey the benefits of partnership for patients, families, and other stakeholders.
- **Develop lessons learned, including from related and intersecting areas.** As partnership efforts increase, building mechanisms for evaluation into the work—for example, assessing the extent to which PFA involvement influenced project outcomes—can facilitate the development of lessons learned. New tools can be developed to help capture this data in more standardized ways. In addition, learning about partnerships with patients and families in other areas—mental and behavioral health, criminal justice, special education, early intervention, disability, and child and family welfare—can identify factors that may contribute to (or hinder) successful partnerships in the opioid work.



“The opioid epidemic is hitting people personally – there are so many people working within the health care system who have personal experiences. Being able to draw on those experiences is cathartic as people come together.”

– PFA Summit Participant

Conclusion



The PFA Summit demonstrated the power and possibility of partnership, with multiple stakeholders coming together to learn from and share ideas with each other. In seeking to advance progress toward patient- and family-centered approaches to the opioid epidemic, it is imperative to not only listen to but also work in partnership with patients and families, and especially with individuals with lived experience. Collaborative action is required to advance this work—educating and preparing key stakeholders, explicitly creating opportunities to purposefully include PFAs, and gathering and sharing lessons learned to inform continued and expanded partnerships. The development of authentic partnerships requires respectful relationships that are grounded in a compassionate environment. While this process may take time, partnerships with patients and families can ultimately accelerate the pace of change.



Appendices

Appendix 1. PFA Summit Participants

Individuals who contributed to the PFA Summit as speakers and members of reactor panels are indicated with an asterisk. The positions listed are those that individuals held at the time the PFA Summit was convened.

Patient and Family Advisors

Annemieke Ambrosier
PFAC Member
St. Mary's Hospital

David Andrews
Patient Advisor

Tara Bristol Rouse
PFE Project Consultant
AHA / HRET

Martie Carnie
Senior Patient Advisor
Brigham and Women's Hospital

Cathy Castillo
Patient Family Partner
Stanford Medical Center

Desiree Collins-Bradley
National Faculty
TCPI

Cherie Craft*
Founding CEO / Executive Director
Smart from the Start, Inc.

Bev Crider
Patient and Family Advisor
Beaumont Health

Katie Donovan
Executive Vice President
Families Against Narcotics

Donna Drouin
Independent Advisor
Healthcare Connection

Lynn Ferguson
PFAC Member
Vanderbilt University Medical Center

Donald Folberg
Advisor
University of Wisconsin

Joan Forte
Patient / Family Partner
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Cheryl Garove
PFAC Advisor and Communications Specialist
Brookwood Baptist Health

Vickie Gross
Patient Advisor
Augusta University Medical Center

Catherine Hanson
Patient Research Participant
Brigham and Women's Hospital

Chase Holleman*
Rapid Response Team Program Navigator
UNC-G Center for Housing and
Community Studies

D'Anna Holmes
Patient Engagement Program Manager
Astellas Pharmaceuticals

Jon Kerstetter
Author
New Centurion

Barbara Kivowitz
Advisor / Consultant / Author
Stanford Health Care

Julia Lanham
Patient / Family Advisor
Carolinas Healthcare System

Amy Ma
Co-Chair, Family Advisory Forum
Montreal Children's Hospital

Tamela Milan-Alexander
MCH Partnership and Outreach Worker
Access Community Health Network

Appendix 1. PFA Summit Participants, Patient and Family Advisors continued

DeeJo Miller
Program Manager, PFE
Children's Mercy Kansas City

Julie Moretz
Chief Experience Officer / AVP
Augusta University Medical Center

Lisa Morrise
Patient and Family Advisor
Consumers Advancing Patient Safety

Skyler Morrise
Patient and Family Advisor
Utah State University

Ruth Nabisere
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CHA Cambridge Health Alliance

Nanci Newberry
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TMF Health Quality Institute

Malisa Pearson
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FREDLA

Lisa Petke
Family Advisor
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Brendaly Rodriguez
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FLCHW Coalition / Oppia Health

Anna Rychtera
Patient and Family Advisor
BC Patient Safety and Quality Council

Susan Sanmann
PFAC Member
St. Mary's Hospital

William Westmoreland
Supply Technician
Evans Army Community Hospital

National Partners

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Colorado Coalition for the Homeless –
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Charon Burda
Assistant Professor, FCH Director,
Psychiatric / Mental Health
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Liz Crocker
VP, Board of Directors
IPFCC

Nancy DiVenere
Board Member
IPFCC

Patricia Fanflik
Public Health Analyst
HHS / HRSA / MCHB

Appendix 1. PFA Summit Participants, National Partners *continued*

Karen Fisher*
Chief Public Policy Officer
AAMC

Susan Grant
Executive Vice President and
Chief Nursing Officer
Beaumont Health

Allison Havens
Nurse Manager, Perioperative
Quality and Safety
Beaumont Health

Bruce Hillenberg
Chief, Pain Management Services
Beaumont Health

Tandrea Hilliard
Health Care Policy Researcher
American Institutes for Research

Jeneen Iwugo*
Deputy Director, Quality Improvement
and Innovation Group
Centers for Medicare & Medicaid Services

Cara James
Director, Office of Minority Health
Centers for Medicare & Medicaid Services

Michelle Johnston-Fleece*
Senior Program Officer
National Academy of Medicine

Harold Kudler
Acting Assistant Deputy Under Secretary
Veterans Health Administration

Carol Levine
Director, Families and Health Care Project
United Hospital Fund

Natalie McCarthy
Program Director
Vancouver Coastal Health

David Meyers
Chief Medical Officer
Agency for Healthcare Research and Quality

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Patient-Centered Outcomes Research Institute

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Denese Neu*
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Assistant Professor
University of Maryland School of Nursing

Appendix 1. PFA Summit Participants, National Partners continued

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UNC Greensboro

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UNC Greensboro

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Anesthesiologist
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Sandra Taylor
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Mary Minniti
Senior Policy and Program Specialist
IPFCC

Libby Hoy
Founder, CEO
PFCCpartners

Stephen Hoy
Chief Operating Officer
PFCCpartners

Appendix 2. PFA Summit Agenda

TIME	PRESENTERS, REACTOR PANELISTS, AND DISCUSSION
7:45-8:30am	Continental Breakfast, Check in and Networking
8:30-9:00am	Welcome and Opening Remarks <ul style="list-style-type: none"> • Bev Johnson, President/CEO IPFCC and Libby Hoy, Founder/CEO PFCCpartners
9:00-9:20am	Opioid Epidemic: Current State Defined <ul style="list-style-type: none"> • Jeneen Iwugo, MPA, Deputy Director, Quality Improvement & Innovation Group (QIIG) at Centers for Medicare & Medicaid Services (CMS)
9:20am	Patient- and Family-Centered Approaches to Address the Opioid Epidemic
	Presentations <ul style="list-style-type: none"> • Wendy Prins, MPH, MPT, Senior Advisor, Quality Innovation, National Quality Forum • Sue Collier, MSN, RN, Interim Vice President, American Hospital Association / HRET
	Reactor Panel <ul style="list-style-type: none"> • PFA: Chase Holleman, MSW, LCAS-A, Naloxone Program Coordinator, Caring Services of High Point • Roy Soto, MD, Program Director, Anesthesiology Residency, Beaumont Hospital • Brittany Wiley, MEd, Senior Quality Improvement Facilitator, Telligen
	Table Discussions – All Participants
11:00-11:10am	BREAK
11:10-12:00pm	Community Approaches to Address the Opioid Epidemic
	Presentations <ul style="list-style-type: none"> • Penny Mohr, MA, Senior Advisor Patient-Centered Outcomes Research Institute (PCORI) • Denese Neu, PhD, Engagement Officer, PCORI • Stephen J. Sills, PhD, Assistant Professor of Sociology, University of North Carolina—Greensboro
12:00-1:00pm	NETWORKING LUNCH
1:00-1:25pm	Word Cloud Activity Changing the Conversation: The Power of Language <ul style="list-style-type: none"> • Pam Dardess, MPH, VP Strategic Initiatives and Operations, IPFCC
1:25-3:10pm	Overview of Policies to Address the Opioid Epidemic
	Presentations <ul style="list-style-type: none"> • Karen Fisher, JD, Chief Public Policy Officer, American Association of Medical Colleges • Michelle Johnston Fleece, MPH, Senior Program Officer, National Academy of Medicine
	Reactor Panel <ul style="list-style-type: none"> • PFA: Cherie Craft, MEd, Founding CEO/Executive Director, Smart from the Start, Inc. • Wendy Nickel, MPH, Director, Centers for Quality and Patient Partnership in Healthcare, American College of Physicians
	Table Discussions – All Participants
3:10-3:25pm	BREAK
3:25-4:00pm	Commitments, Wrap Up, and Evaluations

Appendix 3. Building a Patient- and Family-Centered and Coordinated Approach to Addressing Opioid Use Disorder

In discussing how to address the multiple interacting factors that contribute to opioid use disorder (OUD), Summit participants described the need to build a patient- and family-centered, coordinated approach to OUD education, prevention, treatment, and recovery. To achieve this, diverse stakeholders from all relevant sectors must partner with each other—and with patients and families.

Care Delivery

- Evidence-based prevention and treatment approaches to OUD that consider the whole person and address social determinants of health
- Outreach into the community to provide prevention, care, and treatment in ways that meet patients “where they are,” including harm reduction strategies and proactive outreach to at-risk populations that includes peers with lived experience
- Team-based, integrated, continuous care that includes shared decision-making and open, respectful communication between patients, families, and care providers
- Development of peer-to-peer networks to support patients in recovery

Education

- Consistent provision of education for all patients prior to opioid prescribing, with tools developed in partnership with patient and family advisors (PFAs) to support comprehensive education and expectation management
- Education for health care professionals about how to talk with patients and families about pain management, opioid prescribing, and opioid misuse
- Partnership with individuals with lived experience in medical and allied health education, including in the development of curriculum and serving as faculty

Research

- Evidence-based research about the effectiveness of prevention and treatment approaches, with broad dissemination of information about best practices to patients and families
- Investigation and development of an evidence base related to non-pharmacological approaches to pain management developed in partnership with PFAs

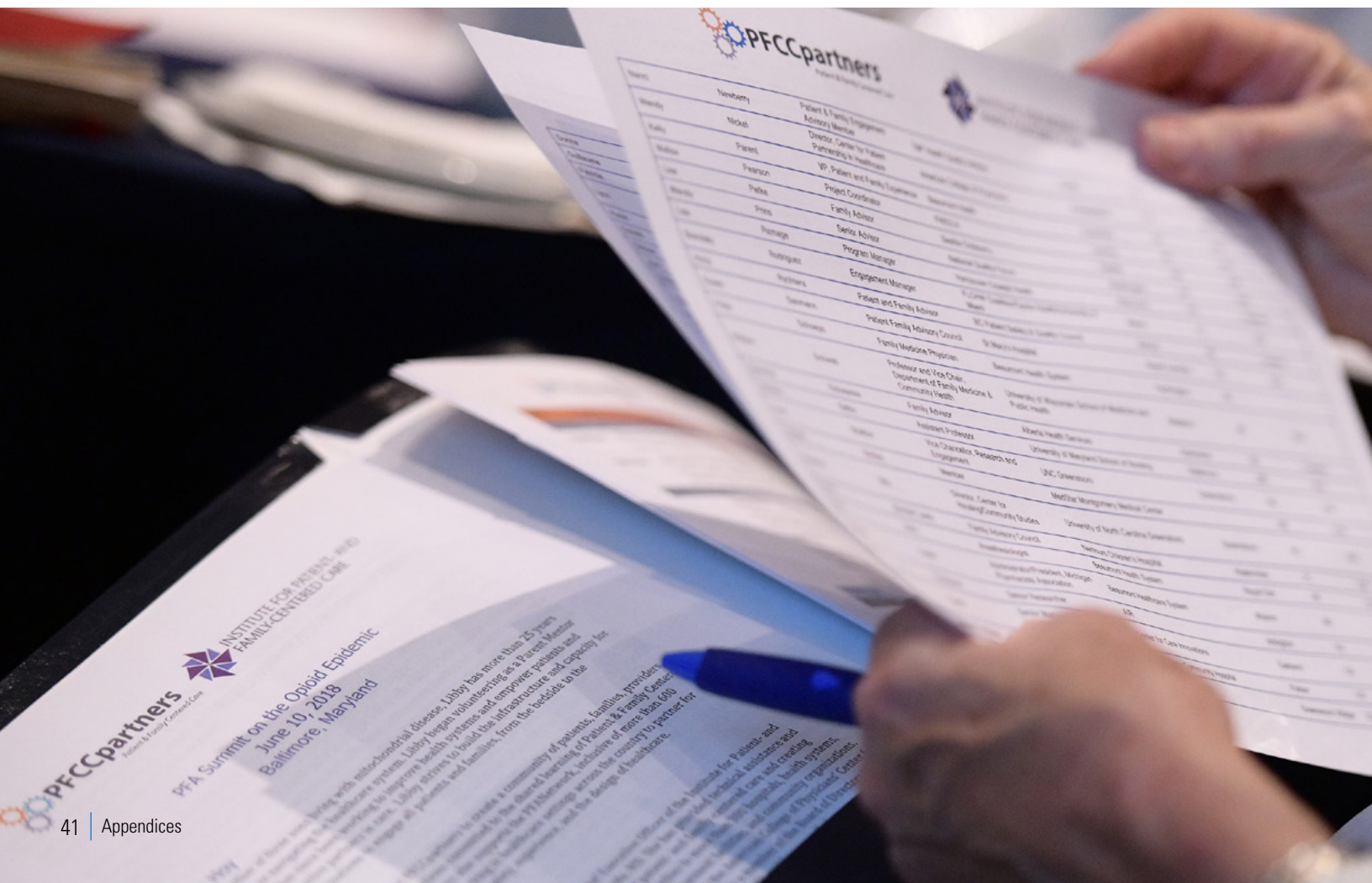
Appendix 3. Building a Patient- and Family-Centered and Coordinated Approach to Addressing Opioid Use Disorder *continued*

Access and Coverage

- Access to and coverage of state-of-the-art OUD treatment programs that address aspects of physical, behavioral, and mental health along with social determinants
- Insurance coverage for alternative pain management therapies, mental and behavioral health services, and patient and family education around opioid use
- Coverage of and reimbursement for services provided to patients by family caregivers

Data Sharing and Transparency

- Mandated data collection and sharing (e.g., related to prescribing practices, overdoses, effectiveness of prevention and treatment programs)
- Transparency around data, including sharing information with patients and families in ways they can understand and use for learning and decision-making



“When you’re an active user, people don’t ask you to come do anything. They’re trying to cast you aside. Very rarely do people take you seriously. But when someone says, ‘No, we want you at the table,’ that gives you a sense of self-worth and purpose. You don’t want to let them down.”

– Lived-experience Project Leader

Appendix 4. Partnering with Individuals with Active Opioid Use Disorder

Partnerships with individuals with lived experience should include not only individuals who are in recovery, but also those who are currently using. These partnerships require open, non-judgmental communication about expectations, along with the development of trusting relationships to support ongoing participation. Lessons learned from project teams that have developed these partnerships include:

- Identify an individual in recovery to serve in a co-leadership role and to set an example for participation. This “lived-experience leader” will play an active role in building relationships with individuals who are currently using.
- The ability of individuals who are currently using to participate as active team members may shift over time. During the recruitment process, interview potential team members—not to screen out individuals who are currently using—but to communicate expectations for participation and mutually assess their ability to participate.
- Develop guidelines for participation and carefully monitor and manage team dynamics and interactions. The lived-experience leader’s role on the team includes immediately addressing issues related to judgment, bias, and respectful communication. Similarly, if a team member becomes disruptive, the leader can address the issue through supportive interactions.
- Support individuals who are currently using in their continued recovery process. Recovery is a personal experience, meaning that individuals will follow different, non-linear, paths. The lived-experience team leader can work with individuals who are currently using to support, and even model, living in recovery.

Appendix 5. Key Stakeholders in Developing Patient- and Family-Centered Approaches to the Opioid Epidemic

Participants at the PFA Summit noted that developing patient- and family-centered responses to the opioid epidemic involves acknowledging the structural and social determinants of health that act as underlying risk factors for OUD (e.g., poverty, disparities in education, housing instability, lack of access to appropriate health care, disparities in the criminal justice system, and other socio-demographic factors). This requires partnership within and between multiple systems and stakeholders to develop strategies that recognize and respond to the complex drivers of OUD. As brainstormed by participants at the PFA Summit, the following is a list of potential stakeholders to engage in developing cross-cutting approaches to the opioid epidemic. The list can be used to help identify stakeholders to partner with as efforts are planned and implemented.



Appendix 5. Key Stakeholders in Developing Patient- and Family-Centered Approaches to the Opioid Epidemic *continued*

STAKEHOLDERS	EXAMPLES
Federal Partners	<ul style="list-style-type: none"> • Centers for Disease Control (CDC) • Centers for Medicare & Medicaid Services (CMS), including CMS programs (Quality Improvement Organizations, Hospital Improvement Innovation Networks) and CMS’s Campaign for Medication Management • Food and Drug Administration (FDA) • Office of Minority Health (OMH) • Patient-Centered Outcomes Research Institute (PCORI) • Substance Abuse and Mental Health Services Administration (SAMHSA) • Veterans Administration (VA)
National Stakeholders	<ul style="list-style-type: none"> • Insurers • National Academies of Medicine • National Quality Forum • Pharmaceutical companies • Press Ganey Associates
Interest Groups and Professional Societies	<ul style="list-style-type: none"> • American Academy of Nursing • American Board of Internal Medicine, including the ABIM Foundation’s Choosing Wisely initiative • American Cancer Society • American Hospital Association • American Medical Association • American Society of Addiction Medicine • Harm reduction organizations
State Health Agencies and State-Level Groups	<ul style="list-style-type: none"> • State-level health care commissions • Area Health Education Centers (AHECs) • State pharmacy agencies • State hospital associations
Health Care Providers	<ul style="list-style-type: none"> • Addiction specialists and treatment professionals • Anesthesiologists • Dentists • ER providers • First responders • Mental and behavioral health care providers • Pharmacists • Physical therapists • Primary care providers • Public health departments • Rural health care providers • Social workers • Surgeons • Visiting nurses

Appendix 5. Key Stakeholders in Developing Patient- and Family-Centered Approaches to the Opioid Epidemic *continued*

STAKEHOLDERS	EXAMPLES
Patient Advocacy Groups and PFAs	<ul style="list-style-type: none"> • American Academy of Pediatrics’ Family Partnership Networks • Disease-specific advocacy groups • Family Voices • National Alliance on Mental Illness (NAMI) • Hospital-based Patient and Family Advisory Councils (PFACs)
Academic and Education Institutions	<ul style="list-style-type: none"> • Dental schools • Medical schools • Nursing schools • Schools of public health • Elementary, middle, and high schools • Parent Teacher Associations (PTAs) • Colleges and universities • Fraternities and sororities
Community Groups and Public Service Groups	<ul style="list-style-type: none"> • Chambers of Commerce • Community social service providers • Homeless shelters • Housing authorities • Mental health and substance use treatment programs • Rotary, Lions, Elks, Masons Clubs • Veterans community groups • YMCA / YWCA
Faith-Based Groups	<ul style="list-style-type: none"> • Faith-based coalitions • Health ministries • Chaplains, spiritual care directors • Black Pastors’ Association • Catholic Charities, Salvation Army, Mitzvah Corps
Law Enforcement and Criminal Justice	<ul style="list-style-type: none"> • Police and Sheriff’s departments • District Attorney’s offices • Public Defender’s offices • Corrections officers • Drug Abuse Resistance Education (D.A.R.E.) program liaisons
Other	<ul style="list-style-type: none"> • Elected officials • NAACP • Native community elders • Latino Coalition

Institute for Patient- and Family-Centered Care (IPFCC)

Founded in 1992 as a nonprofit organization, the [Institute for Patient- and Family-Centered Care](#) (IPFCC) provides national and international leadership for advancing the understanding and practice of patient- and family-centered care in all settings where individuals and families receive health care and support. Patient- and family-centered care redefines the relationships among patients, families, and health care professionals to create mutually beneficial partnerships. It encourages the sharing of information candidly and supportively and fosters the active participation of patients and families in caregiving and decision-making. IPFCC promotes partnerships among patients, families, community members, and health care professionals to enhance health care policy and program planning and implementation; research and evaluation; quality and safety initiatives; and health care professional education.

PFCCpartners

[PFCCpartners](#) is a small organization with a large vision to reinvent the healthcare industry so that hospitals, healthcare organizations, and stakeholders continuously partner with empowered patients and families as a resource in the co-design of healthcare delivery. Built on a foundation of lived-experiences and Advisory efforts, PFCCpartners develops strategies, programs, and structures for the authentic integration of patient and family centered care. We are committed to spreading collaborative partnerships across healthcare that make space for all patients and family caregivers.