

PATIENT AND FAMILY ADVISORY COUNCIL

# Leaders' Guide

for Diagnostic Quality and Safety



SOCIETY<sub>to</sub> IMPROVE DIAGNOSIS<sub>in</sub> MEDICINE

## PURPOSE OF THIS GUIDE

This document is intended to serve as a compendium of best and promising practices for use by Patient and Family Advisory Council (PFAC) members and leaders and those interested in joining or forming a PFAC. While PFACs work on a variety of quality and safety issues, this guide is focused specifically on an often overlooked, but significant, challenge in health care: diagnostic errors. This compilation is based on insights and knowledge shared at the joint Society to Improve Diagnosis in Medicine (SIDM) and National Academy of Medicine (NAM) PFAC convening held in December of 2019,<sup>1</sup> data and guidance from the Health Research & Educational Trust (HRET) Hospital Improvement Innovation Network (HIIN)/SIDM Improving Diagnosis in Medicine Change Package,<sup>2</sup> and, most importantly, from the lived experiences and learnings of many patients and families impacted by diagnostic error. This guide provides foundational education about diagnostic errors and tangible ideas and suggestions for PFACs to employ as they tackle diagnostic quality and safety in their home institutions and systems.

## ACKNOWLEDGEMENTS

The PFAC Leaders' Guide is an initiative of the Society to Improve Diagnosis in Medicine with support from The Mont Fund. Thank you to the National Academy of Medicine for hosting the December 2019 PFAC Meeting.

## INTRODUCTION

### *Why Diagnostic Errors Matter*

Diagnosis is a process that aims to find an explanation for a patient's health problems. Diagnostic error occurs when this explanation is inaccurate, delayed, or not communicated to the patient.<sup>3</sup> Physicians\* are the health care providers most often engaged with making a diagnosis, but other team members, including nurses, lab professionals, and the patient themselves play important roles in helping to determine an accurate and timely diagnosis. To determine a diagnosis, a patient's history, physical examination, lab reports, and imaging studies help clinicians develop a list of possible explanations.

Narrowing in on the correct diagnosis – the true cause of the patient's problem or illness – is very important. It allows the whole health care team, including the patient, to focus treatment in one direction. It also affects all later health decisions.<sup>4</sup> A diagnostic error means that the patient will not receive the correct treatment for the problem or may receive inappropriate treatment for a problem that does not exist. Or the patient may never discover the true problem, so treatment never begins, and the underlying condition worsens. These errors can lead to serious harm or even death. Errors in diagnosis also can increase costs to the health care system and society at large and comprise a significant fraction of avoidable healthcare costs.

Sadly, diagnostic errors are common. Studies in primary care clinics found that one in 20 adult patients will experience a diagnostic error every year,<sup>5</sup> and roughly speaking, 10 percent of suggested diagnoses are probably

wrong.<sup>6</sup> Most diagnostic errors will arise in ambulatory care settings, where most medical care is delivered, but there are also many that arise in the emergency room and in hospital settings.<sup>7</sup> The National Academies of Sciences, Engineering, and Medicine (NASEM) concluded that

***"It is likely that most of us will experience at least one diagnostic error in our lifetime, sometimes with devastating consequences."<sup>8</sup>***

Fortunately, the vast majority of diagnostic errors do not cause serious harm, but a small percentage do, and given the millions of diagnoses rendered in the United States every day, the aggregate harm is appreciable. Autopsy studies suggest that 40,000 to 80,000 hospital deaths annually are attributed to diagnostic errors,<sup>9</sup> which would rank in the top 10 for all causes of death. Studies of malpractice claims support the findings that diagnostic errors are the most common cause for serious harm, accounting for the highest costs per case, and the most catastrophic outcomes.<sup>10</sup> The "Big 3" categories of cancer, vascular events, and infections account for the largest fractions of cases in these studies.

There are too commonly appreciable delays in diagnosing other common, chronic, ambulatory conditions, such as asthma, anemia, diabetes, hypertension, and early forms of kidney disease.<sup>11</sup> More timely intervention in these conditions could help improve long-term outcomes. Diagnostic errors are very costly – patients harmed may suffer disability, pain, unnecessary interventions, reduced productivity with its financial costs, and in extreme cases, loss of life. For example, a delayed



#### THE MISSED TEST

Julia Berg was a perfectly healthy 15-year-old from Minnesota enjoying her summer vacation and looking forward to the fall swim season. As July was winding to a close, she began to feel under the weather. She was lethargic, had a sore throat and a fever. When her nose started bleeding and wouldn't stop, her parents took her to an urgent care clinic.

[READ MORE.](#)

*\*Physician assistants, nurse practitioners, nurse midwives, nurse anesthetists, and others also diagnose illnesses and conditions.*

sepsis diagnosis can result in longer hospitalization, more expensive care in specialty units, and long-term consequences such as amputation of an affected body part. These complications lead to additional costs, such as rehabilitative therapy and assistive devices, and may affect the ability of the person to continue in their current job, resulting in lost wages. As the costs of health care increase, the financial impact of diagnostic errors rises as well.<sup>12</sup>

hospital. Elements of the diagnostic process can include:

- Clinical history and interview (physician asking questions about the problem and medical history)
- Physical exam (physician examining the patient)
- Diagnostic testing (lab tests, x-rays, and other studies)
- In some cases, referral and consultation with a specialist

### The Process of Diagnosis

Optimal patient outcomes are dependent on an accurate, timely diagnosis that is followed by appropriate, timely treatment, all within a supportive system and culture. To understand what diagnosis entails, it can be helpful to visualize diagnosis as a process.

As the figure from NASEM shows, the process begins when people experience a health problem. (See Figure 1.) They engage with the health care system by contacting or going to the doctor's office, a clinic, or a

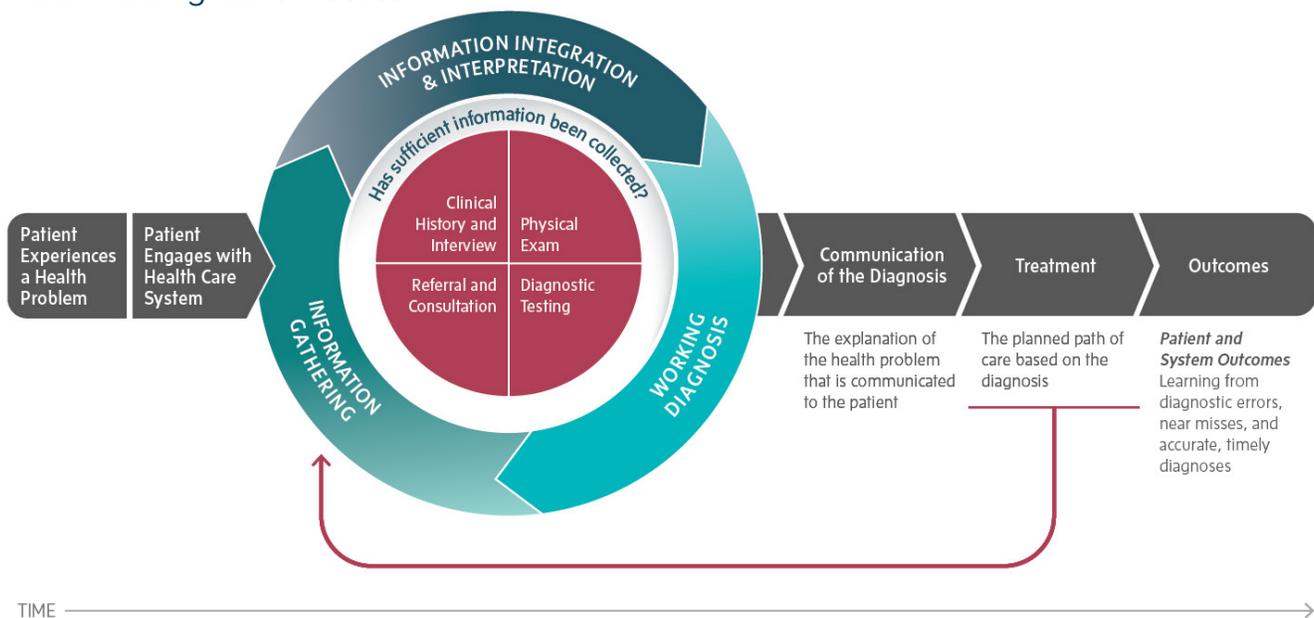
Throughout the process, clinicians are thinking about what might be causing the patient's problem. Formulating a diagnosis is a dynamic process. It involves gathering information, seeing how the various pieces of information fit together, and considering specific diseases that might be possibilities. The 'differential diagnosis' represents a prioritized list of the top possibilities. Sometimes the most likely choice is designated to be the 'working diagnosis,' meaning that it is likely, but hasn't been confirmed, and that other diseases haven't been ruled out. At this point, the clinician should explain the working diagnosis to

#### SPOTLIGHT ON SUCCESS

Anne Arundel Medical Center's Patient and Family Advisors have collaborated on numerous important initiatives including a bedside rounding initiative.

[Learn more about them here.](#)

**FIGURE 1.** The Diagnostic Process



Used with permission from the National Academies of Sciences, Engineering, and Medicine's *Improving Diagnosis in Medicine* report.

the patient and should co-create a treatment plan with the patient based on the diagnosis. The treatment results in an outcome – ideally, improved health.

This process map makes it easier to see where gaps or errors can occur. As Figure 2 shows, failures can occur from the time patients attempt to engage with the health care system all the way through to communication of the diagnosis – or lack thereof – and treatment for the suspected issue. They can occur when patients neglect to mention an important symptom they are experiencing. They can occur during clinicians' integration of information or collection of data, or when clinicians attempt to communicate the diagnosis but do so in a way that is not understandable to patients. They can also occur when clinical systems are not designed to support accurate and timely diagnosis – such as when test results fail to be communicated. Similarly, when patients see specialists after a referral from their primary care physician, it is not uncommon for important

information to be lost in the transition or unavailable because of firewalls or lack of interoperability between clinics, hospitals, or health systems.

When a diagnostic error occurs, reviewing each step in the process and asking, "What if?" can help identify ways to improve the process and reduce future harm associated with diagnostic errors. Cal Sheridan's experience is illustrative.

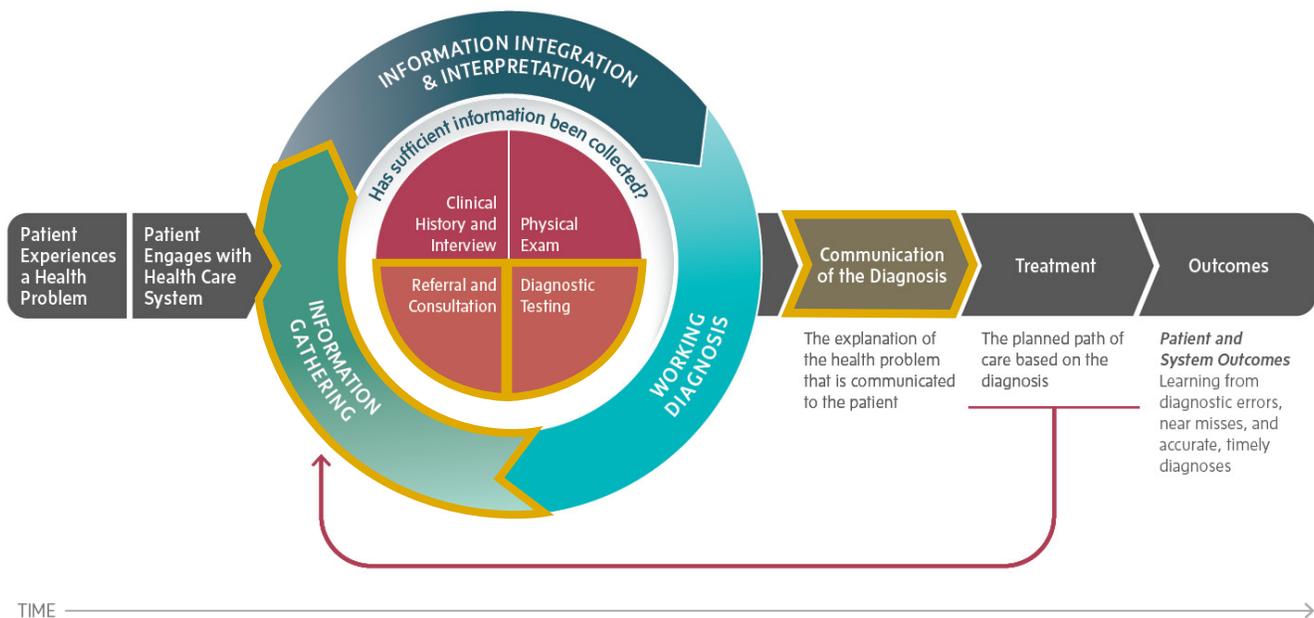
Cal was born two weeks early. He developed jaundice soon after birth; nurses noted this finding several times in their notes. However, the finding was not communicated to his parents, and lab tests to assess the severity and cause were not conducted. He was discharged 33 hours after birth with a recommendation to follow up in two weeks.

On Day four after birth, Cal was floppy and difficult to awaken. His parents called the hospital to report the concerning symptoms. The concerns were dismissed because the nurse considered the first-time mom to be

### UNDERSTANDING DIFFERENTIAL DIAGNOSIS

Often, a patient's symptoms will fit the criteria for more than one condition, so a clinician will prioritize the list of possibilities in the order of "most likely" to "least likely," and may try to exclude some of the possibilities by asking more questions, through further testing or observation, or sometimes a trial of treatment. For example, someone with a runny nose in the Spring might have allergies, a cold, a sinus infection, or, much less likely, something more serious.

**FIGURE 2.** Focusing on Four of the Errors in Cal Sheridan's Diagnostic Journey



Used with permission from the National Academies of Sciences, Engineering, and Medicine's *Improving Diagnosis in Medicine* report.

overreacting. The parents then took Cal to the pediatrician, where the parents' concerns were also dismissed. They finally took Cal to the hospital. A bilirubin test was drawn; the level was the highest ever recorded at the hospital. There was no referral to the NICU and an abnormal result on a brain MRI was not communicated to Cal's parents.

Cal received standard phototherapy and was discharged home. He continued to have difficulty breastfeeding and displayed frequent startle reflex to noise. At 16 months Cal was diagnosed with classic kernicterus due to blood type incompatibility. Today, he lives with permanent neurologic disabilities caused by a condition that could have been prevented if correctly diagnosed at the time.

There are several sources of failure that led to diagnostic error in Cal's case. Consider how these could have been prevented:

- What if there had been a systematic, universal pre-discharge bilirubin test required for all newborns?
- What if Cal's parents had been empowered members of the care team and:
  - had been equipped with discharge information about the risks of newborn jaundice and the availability of a bilirubin test,
  - had been heard and believed, so that the symptoms they were reporting were integrated into the diagnosis, and
  - had been provided access to his medical records and medical notes (e.g., OpenNotes®<sup>13</sup>) via a patient

portal so that they were able to see critical information that wasn't verbally shared?

- What if Cal's parents had access to and were aware of a rapid response team that they could activate when they were concerned about changes or signs of a problem?
- What if there were an alert system in place that would trigger an automatic NICU transfer for extremely high bilirubin levels?

### **Improving Diagnostic Quality and Safety**

The aim of diagnostic quality and safety is to eliminate diagnostic errors and achieve the kind of health care that we all want for ourselves and our loved ones. SIDM, in collaboration with the Health Research & Educational Trust (HRET) Hospital Improvement Innovation Network (HIIN) and a group including experts in diagnostic safety and leaders of healthcare organizations, recently endorsed a group including experts in diagnostic safety and leaders of healthcare organizations recently endorsed a consensus set of [five recommendations to improve diagnostic quality and safety in practice](#). These are:<sup>14</sup>

- Improving teamwork in diagnosis
- Improving the reliability of the diagnostic process
- Engaging patients and family members
- Optimizing clinical reasoning
- Improving learning about and from diagnostic errors

It can be helpful to understand what each of these changes involves.

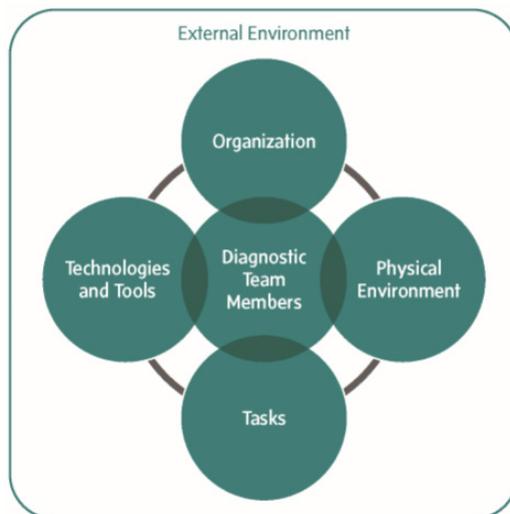


#### **RUNNING AGAINST THE CLOCK**

John Alexander James was a computer science student at Baylor University. At 19 years old, he was healthy, enjoying the start of his third year in college with a bright future ahead of him.

[\*\*READ MORE.\*\*](#)

**FIGURE 3.** The Work System in Which the Diagnostic Process Takes Place



Used with permission from the National Academies of Sciences, Engineering, and Medicine's *Improving Diagnosis in Medicine* report.

### **Improving teamwork in diagnosis.<sup>2,3</sup>**

A patient's care providers must have certain diagnostic skills and must work together as a team. Each team member must take on specific tasks and communicate with others on the team. Teamwork can be improved by making sure the team includes a variety of care providers, as well as patients and families. Teamwork is more effective when team members engage patients and families and adopt key safety practices. For example, effective diagnostic teams use "diagnostic timeouts" where any team member can halt the diagnostic process to voice a concern. Adopting a team-based framework for diagnosis, it is believed, would help catch many diagnostic errors before there is harm, as 'fresh eyes' help catch mistakes.

### **Improving the reliability of the diagnostic process.**

A reliable process is one where steps occur without delays or mistakes. Creating a reliable diagnostic process requires that structures within the care setting (hospital, clinic, etc.) exist to prevent diagnostic errors. It also requires that the flow of clinical services and information work well. For example, there must be a dependable way

for care providers to follow up with patients who have been seen in the emergency department. Specialists must be available to see patients if needed. Systems must be in place to ensure that test results are communicated reliably and in a timely manner. A major expectation of reliable care is that patients can be seen in a timely manner.

### **Engaging patients and family members.**

Patients and families sometimes see safety risks that staff members have overlooked. Actively involving patients and families is essential for improving diagnostic quality and safety. An effective way to engage patients and families is including them on the diagnostic team. For example, the care team can include patients and families in bedside rounding where they discuss results and the working diagnosis. Patients can also access the patient portal for lab tests and clinical notes, report concerns, and activate rapid response teams when critical issues arise. Ideally, patients should be engaged participants throughout the entire diagnostic process.<sup>4</sup>



### **SPOTLIGHT ON SUCCESS**

MedStar Health worked with its patient and family advisors to create a sepsis awareness and education campaign which included this powerful and informative video.

**[WATCH HERE.](#)**

A second way is including patients and families outside of their own care in the broader operational work of the hospital or clinic. For example, hospitals can train and mobilize PFACs to co-produce diagnostic safety solutions, include patients and family members in patient safety committees and activities, and include patients and families in root cause analysis (RCA), to identify causes and plans of action to prevent similar errors in the future.

**Optimizing clinical reasoning.**

Perhaps the most critical step in the diagnostic process is the work done by the clinicians who synthesize the available information to arrive at the most relevant diagnostic possibilities. Clinical reasoning can be defective if information is incorrect or missing, if the clinician's knowledge base is limited, or by any number of factors that detract from optimal decision-making, including stress, distractions, pressure of time, or other factors.

Among the most promising methods that can improve cognitive performance is the use of clinical decision support, which can help clinicians arrive at the most appropriate set of diagnostic possibilities. Other options include using reflection during the clinical reasoning process, or asking others (usually peers or consultants) to provide second opinions on a case. The functionality of the electronic medical record in use is another key element that influences the reliability of the clinical reasoning process.

**Improving learning about and from diagnostic errors.** Diagnostic performance can improve by learning from adverse diagnostic events, as well as from diagnoses that go well. Engaging patients, families, and providers to provide feedback is a critical first step to identify both diagnostic errors, and successes. Hospitals can increase awareness of diagnostic errors with workshops for care providers, board members, and hospital



**FROM A SMALL SCRAPE TO SEPSIS**

Rory Staunton was a 12-year-old boy with the dream to grow up to be a pilot—he had fallen in love with the story of “Sully” and the miracle landing of the disabled jet on the Hudson River. Rory was diving for a ball in the school gym one day. He got the ball but scraped his arm.

**[READ MORE.](#)**

## HOW PATIENTS AND FAMILIES IMPROVE SAFETY

The active involvement of patients and families is very important for reducing diagnostic errors. Too often, diagnostic errors are not reported. This prevents care providers, hospitals, and clinics from being able to learn from errors. Patients and families often notice important safety issues. When invited to voice their concerns, patients and families can give valuable feedback. This feedback allows hospitals and clinics to fix a diagnostic error and prevent similar errors in the future.

PFACs can be effective at delivering feedback about risks, errors, and possible solutions. However, not all hospitals and clinics have PFACs. Those that do sometimes fail to ask for their input on safety matters.

Certain factors support the successful involvement of PFACs in safety work. These include:

- Leaders believe that patients and families have unique expertise and knowledge.
- Leaders' actions show their commitment to this belief.
- There is a staff liaison working actively with the PFAC.
- PFAC members are asked to provide feedback on possible safety concerns.
- The staff liaison communicates back to PFAC members about outcomes from their previous feedback and suggestions.
- PFAC members are asked to help identify priority safety areas.
- PFAC members are invited on regular "walkabouts," where they tour the organization and give feedback on possible safety concerns.

These attributes are essential to facilitate the successful involvement of PFACs in improving safety. One study found that hospitals that had PFACs achieved better quality and safety scores than those without PFACs.<sup>15</sup> In addition, there are recognized best practices that have been shown to make PFACs more effective. (See Figure 4.) Hospitals with PFACs that followed best practices achieved better results on Centers for Medicare & Medicaid Services (CMS) quality and safety measures than hospitals with PFACs that did not.

PFACs have the capacity to improve safety for several reasons:

- Patients and families observe care across all settings (for example, outpatient clinics, emergency departments, and/or post-surgical recovery units), while care providers and leaders often see care provided within a limited or narrow context. The observations of PFAC members provide valuable information about areas of risk.
- PFACs are very powerful at driving change. When PFAC members share personal stories about diagnostic error, care providers and leaders better understand the impact of errors and the urgent need to prevent them.
- PFACs have access to the local community. PFAC members can effectively share information with community members to help them navigate their healthcare experiences.
- The role of PFACs is expanding due to CMS requirements and the Patient-Centered Outcomes Research Institute's current research agenda.<sup>16,17</sup> This means that PFACs will have even more opportunities to give input about errors in the future.



Michael McGinnis engages PFAC leadership to learn how to drive patient engagement in hospitals and health systems to improve diagnostic quality and safety.

FIGURE 4.

## EXEMPLARY PFACS—BEST PRACTICES

### PFAC structure and membership

- The PFAC has an executive sponsor and staff liaison.
- There is a defined relationship between the PFAC and the hospital/health system leadership and board of directors.
- More than 50% of PFAC members are PFAs; PFAs are representative of the patient populations served.

### Recruitment

- Recruitment is an ongoing program rather than a one-time event.
- Recruitment strategies are designed to ensure that the PFAs reflect the diversity of communities served.
- Clinicians and staff members help identify potential PFAs; other contacts and resources available through the hospital are used (e.g., support groups, relationships with community organizations).

### Onboarding and orientation

- Onboarding and orientation are provided to all PFAC members, covering the key elements of the role of a PFA and helping orient PFAs to hospital quality and safety work.

### PFAC operations

- The PFAC meets regularly, approximately 10 times per year.
- There is an agenda for each PFAC meeting, ideally developed by a PFA chair or co-chair, or by the PFAC.
- Language/translation services, childcare, parking/transportation, and even stipends are provided to encourage participation, especially among disadvantaged populations.

### Opportunities offered to PFAs

- The hospital offers a variety of ways to serve as PFAs, including virtual opportunities and full membership on key committees, quality improvement and safety teams, and governing boards.

### Feedback, evaluation, and reporting

- PFAs receive feedback about the impact of their work.
- There is an annual PFAC evaluation that measures the outcomes and impact of PFAC activities and initiatives.
- An annual report is prepared to summarize PFAC accomplishments and future plans and shared broadly with the health system and the community.

Used with permission from NYS Health Foundation's Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals report.

## ENGAGING TOP LEADERS

PFACs can be powerful drivers of change. PFAC members are the most direct contact that organizational leaders have with the people they ultimately serve. PFACs provide an important source of valuable information – information that can help leaders make decisions that improve the patient experience, while reducing waste and redundancy and improving organizational performance. As a PFAC leader, you have an influential role in driving change and reducing diagnostic errors.

The active involvement of top leaders at your hospital, health system, or clinic in diagnostic quality and safety is important to making progress. Top leaders:

- Create and maintain safety culture, one where diagnostic safety is prioritized, and care providers are encouraged to look for and report errors.
- Set the priorities of the organization, which results in more attention on certain programs and tasks.
- Allocate resources, both money and staff time.

Here are five steps you can take to leverage your PFAC's influence and drive change:



**Educate your PFAC about diagnostic quality and safety**



**Connect with top organizational leaders**



**Provide opportunities for your community to learn about the diagnostic process**



**Advocate for full engagement of patients and families in preventing diagnostic error**



**Advocate for systems and processes to improve diagnostic quality and safety**

Knowing how to execute on these steps may seem challenging at first. Specific suggestions are provided below.



### **Educate your PFAC about diagnostic quality and safety**

- Include diagnostic quality and safety as a regular item on your meeting agenda.
- Include a member with a direct experience with diagnostic error.
- Identify patient/family stories related to diagnostic error to share.
- Invite experts to speak about diagnostic quality and safety.
- Use the one-pager to explain diagnostic error.
- Distribute hard copies or share links to the Improving Diagnosis in Medicine change package.



### **Connect with top organizational leaders**

As a PFAC leader, it is important to engage top leaders in your hospitals and systems in improving diagnostic quality and safety. One simple step is asking to give a presentation about diagnostic error and safety to your C-suite or safety colleagues. Through your executive champion or liaison, schedule a time to meet with leaders. Find out what the top safety and quality issues are at the institution and what keeps the leaders “up at night.” When you have opportunities to interact with leadership, be sure to spend time preparing:

- Think about how you can most effectively tell your story or invite another patient/family member to tell theirs. Make sure to craft your story and assist others in crafting theirs so that the stories are the right length and lead to a call to action. Access these tools to help you prepare:
  - [SIDM StoryBank](#)
  - [One-pager on PFAC Convening](#)
  - [How to Tell Your Diagnostic Story](#)
- Ask for questions from leaders and offer to share the presentation with other groups in your organization, such as the quality and safety committee.
- Offer to stay in contact with the leaders and return with updates. Be available for ongoing dialogue.



## Provide opportunities for your community to learn about the diagnostic process

- Use or adapt existing materials.
- Use and share tools:
  - [Checklist for Getting the Right Diagnosis](#): tool created by SIDM with others
  - [Patient Toolkit](#): tool created by SIDM Patient Engagement Committee to help prepare for medical appointments
- Collaborate with your executive champion or liaison to identify funding.
- Consider hosting a community awareness event.



## Advocate for full engagement of patients and families in preventing diagnostic error

- Gather information and take steps to advocate for improvement. You can recommend and work to institute multiple activities at your organization such as:
  - Educating
    - » Teaching the diagnostic process to all disciplines, patients, and families
    - » Educating team members, including patients and family members, about their roles in the diagnostic process and their diagnostic responsibilities
    - » Creating opportunities for PFACs to teach clinicians how to take better healthy histories and record physical information
    - » Teaching clinicians to actively engage in informed decision-making processes
    - » Enlisting PFACs to teach empathy to members of the diagnostic team using an established or locally-developed curriculum
  - Creating a culture of patient engagement in diagnosis
    - » Requesting active engagement of PFAC members on quality improvement teams and committees, in governance, and at new hire orientations
    - » Having systems for patients and families to give ongoing feedback during the course of illness
    - » Creating an environment and processes that make patients and family members feel comfortable requesting specialty expertise
    - » Engaging patients and families in diagnostic improvement efforts, including offering grand rounds and co-developing new processes, policies, and diagnostic materials
    - » Identifying opportunities for patient and family engagement (e.g., bedside huddles)

- Fostering transparency
  - » Providing full transparency to patients, families, and caregivers for clinical documentation (e.g., OpenNotes)
  - » Developing and using a patient-centered approach for early disclosure of adverse events
  - » Having a method to achieve an amicable and fair resolution for the patient, family, and involved health care providers (e.g., CANDOR)
- Promoting open communication
  - » Having a communication tool for patients and families that identifies risk of diagnostic error (e.g., a diagnostic charter or consent for clinical care)
  - » Routinely discussing diagnosis and expected clinical course with all team members (including family/patient as team members)
  - » Using and evaluating patient communication devices such as whiteboards, iPads, OpenNotes, and patient portals to improve communication with patients and their families



### **Advocate for systems and processes to improve diagnostic quality and safety**

- Gather information and take steps to advocate for improvement. You can recommend and work to institute multiple activities at your organization such as:
  - Promoting interprofessional teamwork and training
    - » Suggesting to leadership the value of working in diagnostic teams that include patients and family members as defined in the in the NASEM report *Improving Diagnosis in Health Care*
    - » Promoting an increased awareness of diagnostic harm and errors through incorporating patient and family stories and participating in grand rounds, board of trustee and senior management education, visiting professor rounds, faculty development conferences, etc.
  - Creating or maintaining effective systems/processes
    - » Advocating for use of a follow-up system that reliably closes the information loop (lab/radiology/clinical process management systems) and ensures reporting of test results that return after discharge (e.g., the discharge summary contains list of pending test results) and communicating them to patients
    - » Helping create a patient-centered process for conveying the degree of diagnostic uncertainty a clinician has for a specific diagnosis of a patient



PFAC leader, Amy Kratchman, shares her story with the group to inspire others to work to improve diagnostic safety.

- » Encouraging adoption of a process for simple and anonymous reporting of diagnostic errors by all members of the diagnostic team, including patients and clinicians outside of the specific health care system performance feedback loop
- » Promoting reliable, routine, and timely feedback processes for communicating diagnosis to emergency department, patient and family members, providers, and diagnostic team
- » Advocating for a clearly defined escalation path for deteriorating clinical conditions and an early warning system to alert clinicians about clinical deterioration (e.g., PEWS, MEWS)
- » Helping create a process for obtaining and reviewing patient experience feedback in order to assess diagnostic performance (ensure that this is not only about "experience" but "how we ended up" as patients - what the actual outcomes were)

## CALL TO ACTION

What are some actions that PFAC leaders can take to improve diagnostic quality and safety? PFAC leaders can:

- Assess the current status of awareness of diagnostic errors in your PFAC and at your organization, and provide links to supporting materials such as
  - [\*Improving Diagnosis in Health Care\*](#): a report from NASEM (available free as download)
  - [\*Facts About Diagnostic Error\*](#): SIDM web page with FAQs
  - [\*Diagnostic Error: Learning From the Past and the Present\*](#): newsletter article on diagnostic error
  - [\*Dx IQ\*](#): SIDM blog on patients and accurate and timely diagnosis
  - [\*Improving Diagnosis in Medicine Act of 2019\*](#): information about legislation introduced in the House of Representatives
- Engage with your organization and ensure diagnostic quality and safety is on the radar of leaders (as described previously).
- Connect with other PFACs and share tips about improving safety.
- Include diagnostic error on the agenda of your PFAC meetings, including information from the SIDM convening that occurred in December 2019.
- Educate patients and families about the diagnostic process:
  - Use the diagnosis flow chart as a tool for mapping out diagnostic errors and facilitating conversations about errors; see Diagnostic Process Mapping (Figure 2)
  - Use and share tools:
    - » [\*Checklist for Getting the Right Diagnosis\*](#): tool created by SIDM with others
    - » [\*Patient Toolkit\*](#): tool created by patients to help prepare for medical appointments

## TAKE HOME POINTS

Diagnostic errors occur too often and can have devastating consequences for patients and families. There are recognized methods for reducing these errors. A key approach is involving patients and family members. Patients and families may observe possible safety risks that are missed by clinical staff. PFACs are powerful mechanisms for improving diagnostic quality and safety. PFACs that follow best practices are more likely to be effective.

One of the most effective ways to reduce diagnostic errors is engaging top leaders. PFAC leaders are in an ideal position to share powerful information about diagnostic errors with C-suite leaders. Sharing data and patient stories will encourage them to prioritize diagnostic quality and safety. Health care organizations that work with PFACs can reduce the number of diagnostic errors that occur and avoid preventable harm to patients and negative impacts on families.

PFAC leaders can also foster improvement by adding diagnostic error to their PFAC's strategic focus, connecting with other PFACs, and educating patients and families.

## THANKS TO THOSE WHO PARTICIPATED IN THE DECEMBER MEETING:

**Ayodola Anise**, National Academy of Medicine

**Erin Balogh**, National Academy of Medicine

**Victoria Bayless**, Anne Arundel Medical Center

**Susie Becken**, Kaiser Permanente

**Chrissie Blackburn**, University Health

**Steven Coffee**, MedStar Georgetown University Hospital

**Desiree Collins Bradley**, Texas Children's Hospital

**Anna Cupito**, National Academy of Medicine

**Vanessa Deen Johnson**, Stanford Healthcare

**Cheryl Douglass**, MedStar Health & Anne Arundel Medical Center

**Paul Douglass**, MedStar Health & Anne Arundel Medical Center

**Paul Epner**, Society to Improve Diagnosis in Medicine

**Steven Faust**, Emory University Hospital

**Lynn Ferguson**, Vanderbilt University Medical Center

**Fasika Gebru**, National Academy of Medicine

**Amy Grigg**, Anne Arundel Medical Center

**Nicole Gudzowsky**, Johns Hopkins Health System

**Silver Hannon**, Society to Improve Diagnosis in Medicine

**Martin Hatlie**, Consumers Advancing Patient Safety

**Pat Holle**, Anne Arundel Medical Center

**Libby Hoy**, Patient-and-Family-Centered-Care Partners

**Ann Jackson**, University of Chicago Medicine

**Beverley Johnson**, Institute for Patient-and-Family-Centered Care

**Lisa Juliar**, Minnesota Alliance for Patient Safety

**Amy Kratchman**, Children's Hospital of Philadelphia

**Lydie Marc**, Health Research and Education Trust

**Michael McGinnis**, National Academy of Medicine

**Monica Mewshaw**, Anne Arundel Medical Center

**David Meyers**, Society to Improve Diagnosis in Medicine

**DeeJo Miller**, Children's Mercy Hospital Kansas City

**Julie Moretz**, Augusta University Medical Center

**Armando Nahum**, MedStar Health

**Barbara Pearson**, University of Chicago Medicine

**Laura Riley**, Peacehealth Sacred Heart Hospital

**Daniel Rodriguez**, North Shore University Heart Hospital

**Sue Sheridan**, Society to Improve Diagnosis in Medicine

**Lorie Slass**, Society to Improve Diagnosis in Medicine

**Leslie Tucker**, Society to Improve Diagnosis in Medicine

## References

1. Society to Improve Diagnosis in Medicine. PFACs in ACTION. <https://www.improvediagnosis.org/act-update-newsletter/pfacs-in-action/>. Accessed April 24, 2020.
2. Health Research & Educational Trust. *Improving Diagnosis in Medicine Change Package*. Chicago, IL: Health Research & Educational Trust. 2018.
3. National Academies of Sciences, Engineering, and Medicine. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press. 2015.
4. National Academies of Sciences, Engineering, and Medicine. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press. 2015.
5. Singh H, Meyer A, Thomas E. The frequency of diagnostic errors in outpatient care: estimations from three large observational studies involving US adult populations. *BMJ Quality and Safety*. 2014;23(9):727-731.
6. Graber M. The incidence of diagnostic error. *BMJ Quality and Safety*. 2013;22, Part 2:ii21-ii27.
7. CRICO Strategies. *Medical Malpractice in America; A 10-Year Assessment with Insights*. Boston, MA 2018.
8. Balogh E, Miller B, Ball J. Improving Diagnosis in Health Care. *National Academy of Medicine*, Washington DC 2015.
9. Leape L, Berwick D, Bates D. Counting deaths from medical errors. *JAMA*. 2002;288(19):2405.
10. Newman-Toker D, Schaffer A, Yu-Moe W, et al. Serious misdiagnosis-related harms in malpractice claims: The "Big Three" – vascular events, infections, and cancers. *Diagnosis*. 2019;6(3):227-240.
11. Singh H, Meyer A, Thomas E. The frequency of diagnostic errors in outpatient care: estimations from three large observational studies involving US adult populations. *BMJ Quality and Safety*. 2014;23(9):727-731.
12. Khullar D, Jha AK, Jena AB. Reducing Diagnostic Errors--Why Now? *N Engl J Med*. 2015;373(26):2491-3.
13. OpenNotes. Everyone on the same page. [www.opennotes.org](http://www.opennotes.org). Accessed April 24, 2020.
14. Health Research & Educational Trust. *Improving Diagnosis in Medicine Change Package*. Chicago, IL: Health Research & Educational Trust. 2018.
15. Institute for Patient- and Family-Centered Care. *Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals*. 2018. [https://ipfcc.org/bestpractices/NYSHF\\_2018\\_PFAC\\_Online\\_v3.pdf](https://ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf). Accessed February 12, 2020.
16. Centers for Medicare and Medicaid Services. *CPC+ Care Delivery Requirements Crosswalk*. 2019. <https://innovation.cms.gov/Files/x/cpcplus-practicecaredlvreqs.pdf>. Accessed February 13, 2020.
17. Patient-Centered Outcomes Research Institute. Building knowledge of how patient-family advisory councils (PFACs) engage with patient-centered outcomes research (PCOR). 2019. <https://www.pcori.org/research-results/2015/building-knowledge-how-patient-family-advisory-councils-pfacs-engage-patient>. Accessed February 13, 2020.



SOCIETY to IMPROVE DIAGNOSIS in MEDICINE