SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

Tackling Diagnostic Error in Your Hospital

A Playbook for your PFAC: Facilitator's Guide

About the Playbook's Author

The Society to Improve Diagnosis in Medicine (SIDM) catalyzes and leads change to improve diagnosis and eliminate harm from diagnostic error. They work in partnership with patients, families, the healthcare community and other stakeholders. SIDM is the only organization to solely focus on diagnostic errors and works to improve the accuracy and timeliness of diagnosis. Their vision is to create a world where no patients are harmed by diagnostic error and work to achieve that vision by providing innovative solutions to reduce medical errors that arise from misdiagnosis, delayed diagnosis, or missed diagnosis.

More information about SIDM can be found on their website: https://www.improvediagnosis.org/.

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Playbook Description

The Facilitator's Guide is designed to help the PFAC leader/facilitator facilitate the discussion with the PFAC over a series of meetings and includes discussion prompts and template examples. Therefore, the Playbook is divided into four sections that could be presented over 4-6 meetings (the completion of the What If template and/or Patient Engagement template, but take more than one meeting). The first three sections end with discussion questions; the final section ends with two exercises to get the PFAC familiar with a set of templates they can use to identify projects.

The Facilitator's Guide includes scripted language to be read or summarized by the PFAC leader while delivering the presentation. The scripted language is provided in the notes section of the slides. The Facilitator's Guide also includes introductory information specifically for the PFAC leader/facilitator to determine, along with hospital leadership, whether the PFAC is ready to pursue work in reducing errors in diagnosis or whether they need additional preparation first.

Note to the facilitator: How to use this Playbook

- This tool is intended for use by PFACs to address diagnostic errors in your hospital or institution. If you are a PFAC member, leader, or liaison, interested in working to reduce errors in diagnosis, you have come to the right place!
- The Playbook is divided into four sections for you to review with your PFAC. Each section should take 10-15 minutes to complete
- There are two versions of the Playbook
  - This facilitator's version includes content on the slides to present to your PFAC, scripted language in the notes under the slides for you to read to or summarize for the PFAC, and discussion questions to help engage your PFAC.
  - The PFAC version includes content (in the slides) and discussion questions, but no facilitator notes or instructions.
- Before you dive in, review the next slide to determine whether your PFAC is ready to pursue this topic or whether it might be helpful to do some foundational work first.

Note to the facilitator: Is your PFAC ready to tackle diagnostic error?

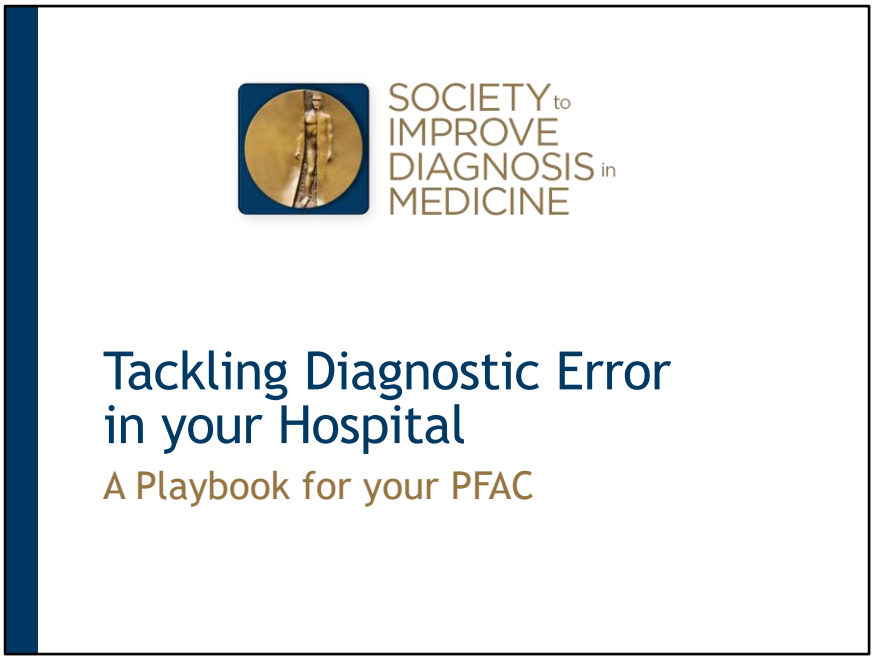
How you prepare your PFAC to begin exploring and working to address diagnostic safety may depend on the resources you have available and how long your PFAC has been established and operating.

- If you are brand new, or perhaps even still in the process of forming the PFAC, there are a wide array of resources available for building, training, and optimizing the work of a PFAC, some of which are described below.
- If you feel that your PFAC is ready to jump in and begin to work on diagnostic safety, this Playbook is your path forward!

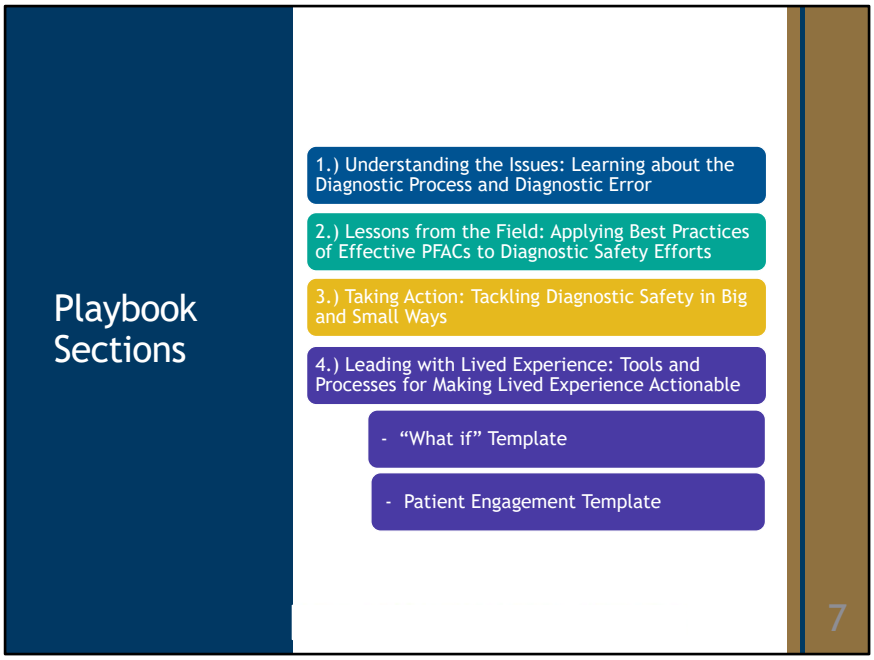
The Institute for Patient and Family Centered Care (IPFCC) has a suite of resources to support the creation and operation of PFACs

Patient Family Centered Care Partners (PFCCPartners) provides resources and support for PFACs and other types of Patient Family Advisors

The American Medical Association (AMA) produced a module on PFAC development in collaboration with Consumers Advancing Patient Safety and ProjectPatientCare.org



We will go through this Playbook over our next few meetings with the goal of learning a little about diagnostic errors and identifying some initiatives we can work on together with our hospital/health system leadership to try to reduce errors in diagnosis, including delayed, wrong, or missed diagnoses, and diagnoses not communicated to the patient.



The playbook is divided into four sections, and we will go through one or two of them at each of our upcoming meetings.

As you can see, first we'll be learning about diagnosis—what clinicians call the "diagnostic process," and how errors occur.
Next, we'll learn about how other PFACs have been successful in working in diagnostic quality and then explore some activities or actions we might want to take.

Section 1

Understanding the Issues: Learning about the Diagnostic Process and Diagnostic Error

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Why should you care about diagnostic safety?

- One in 20 patients in outpatient settings will experience a diagnostic error each year = **12 million Americans** each year
- Patients experiencing medical errors report misdiagnosis **more often than any other error (59%)**
- **40,000-80,000** people die each year from diagnostic failures in U.S. hospitals alone
- Estimates of the costs associated with diagnostic error exceed **$100 billion per year**

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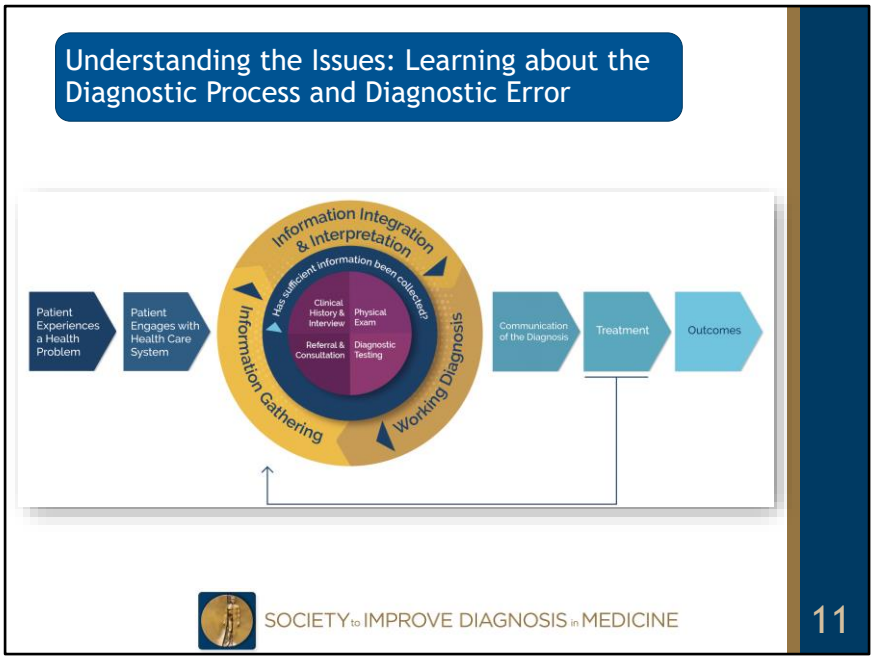
Understanding the Issues: Learning about the Diagnostic Process and Diagnostic Error

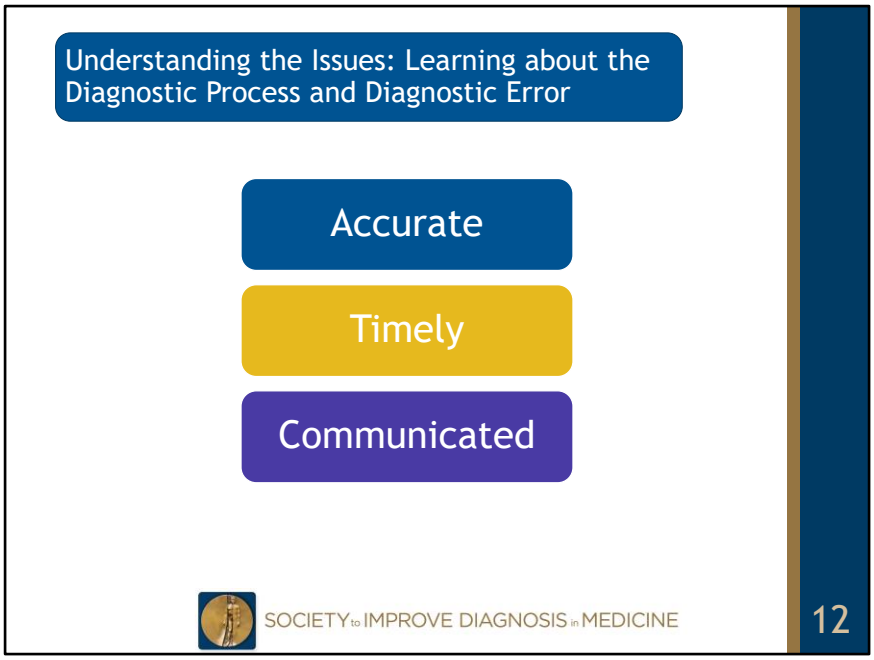
Definition of "Diagnostic Error"

An event where one or both of the following occurred, with harm or high potential of harm to the patient:

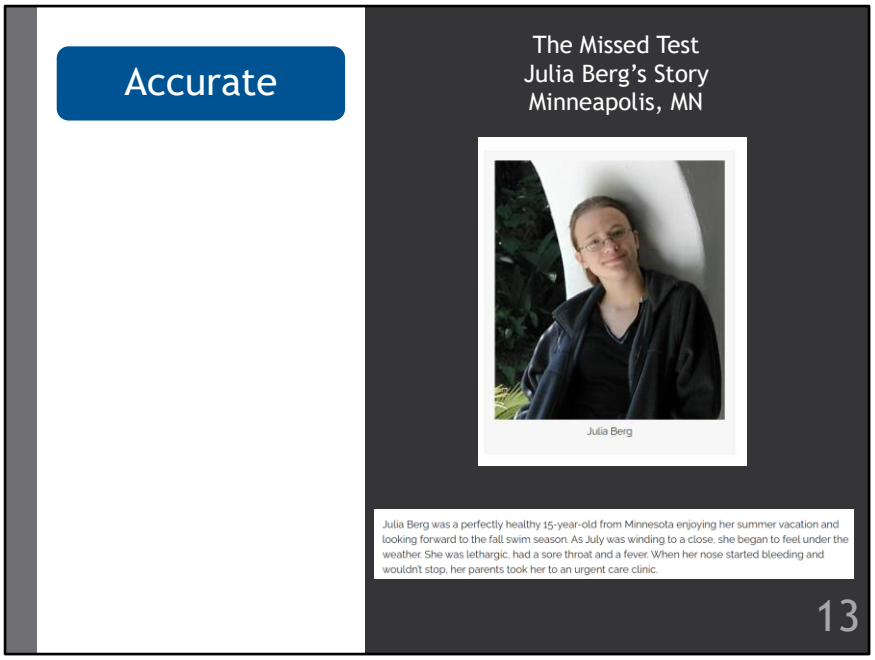
- Delayed, wrong, or missed diagnosis: At least one missed opportunity to pursue or identify an accurate and timely diagnosis based on the information that existed at that time.
- Diagnosis not communicated to the patient: Accurate diagnosis was available but was not effectively communicated to the patient or family.



The diagnostic process starts when a patient experiences a health problem and engages with the health care system (i.e., physician's office, urgent care center, emergency department, etc.). Once the patient engages with the health care system, the process continues as clinicians (i.e., doctors, nurses, radiologists, pharmacists, etc.) gather information from the patient about their health problem. Clinicians than integrate and interpret the information gathered from the patient, often including the results of lab tests or radiology exams, as they start to develop a working diagnosis. Once a working diagnosis is established, clinicians communicate the accurate and timely diagnosis to the patient and establish a treatment plan based on the diagnosis. The process continues as clinicians monitor the patient's outcomes to ensure that the treatment is working, which requires additional information gathering.



Now let's discuss some examples of diagnostic errors. Remember, the key elements of a successful diagnosis are accuracy, timeliness, and communication.



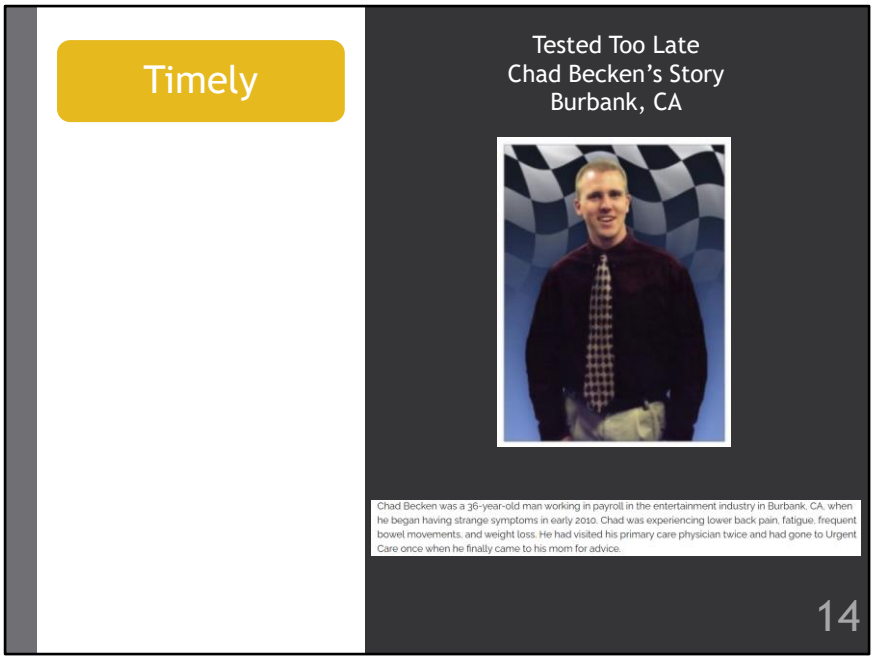
The Society to Improve Diagnosis in medicine, or SIDM, has developed an online Patient StoryBank, where patients or family members share their diagnostic error story so that others can learn from them and use their experiences as teaching tools. These examples of diagnostic error come from the SIDM's Patient StoryBank.

Julia Berg's story is an example of the importance of an accurate diagnosis.

Julia was a perfectly healthy 15-year-old, who began to feel under the weather, experiencing a sore throat, lethargy, and a fever. Initially diagnosed with and treated for a kidney infection, a few days later she was diagnosed with a gallbladder infection, placed on a liquid diet, and scheduled for surgery, but low platelet counts meant the surgery kept getting pushed back. Throughout their time in the hospital, Julia's parents noted how many clinicians seemed puzzled by the diagnosis in such a healthy and fit young woman. Eventually the surgery occurred as planned, but four hours after the surgery, Julia's condition deteriorated, and she died from complications of an undiagnosed case of mononucleosis.

Julia's parents became very active in diagnostic quality after the loss of Julia, including using Julia's story as a teaching tool for students at their local medical

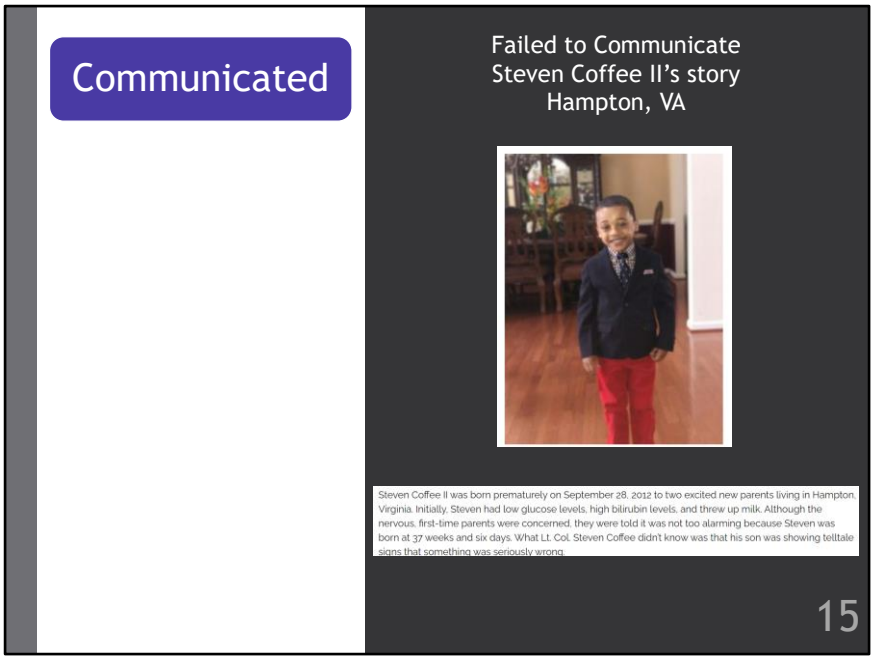
school and hosting educational events in her honor.



Chad Becken's story is an example of the importance of a timely diagnosis.

Chad sought care for an array of worrisome symptoms including low back pain, fatigue, and weight loss. He was seen by several clinicians, some of whom ran tests, but none of them provided answers. By the time Chad, who was 36 years old, was advised to get a colonoscopy, it was too late. He was diagnosed with stage 4 colorectal cancer, and the tumor had penetrated the pelvic wall making removal of the tumor impossible. Chad did undergo treatment for several months, but tragically died at the age of 37.

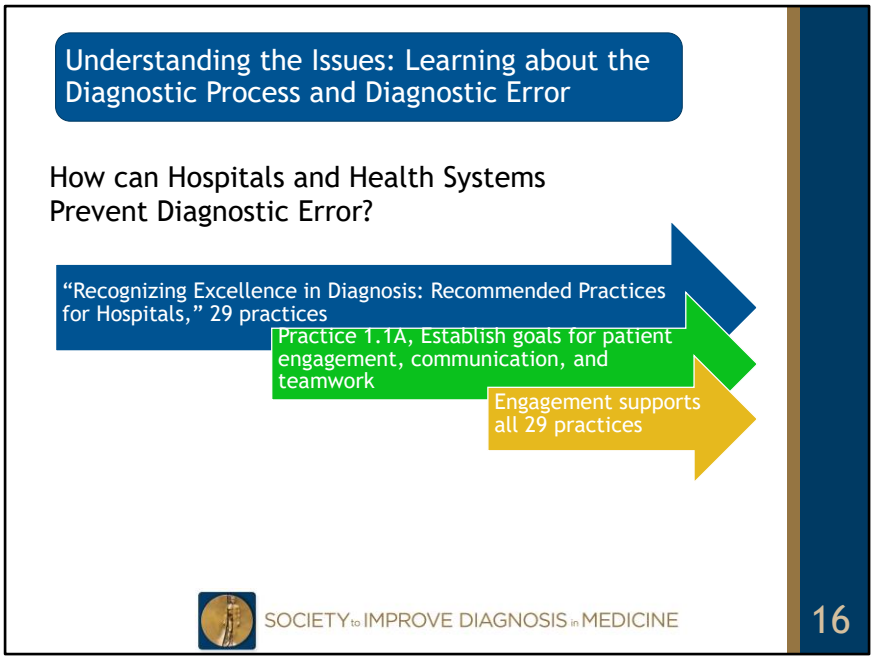
After the loss of Chad, his mother became very active in the patient safety movement, serving on her local PFAC and partnering with SIDM on several diagnostic quality projects.



Steven Coffee II's story is an example of the importance of communication.

Col. Steven Coffee's son was born premature, with low glucose and high bilirubin levels, and an issue with throwing up milk, but he and his wife were assured these things were not too alarming given that their baby was premature. Within a month of his birth however, he was diagnosed with galactosemia, a rare metabolic disorder that makes someone unable to process galactose—a component of milk. Despite being told that the baby had the condition, no one communicated to the family any details about the condition was or how to manage it. Ultimately, complications of the condition caused the baby to develop liver failure and require a liver transplant. Now a healthy young man, these severe complications could have been avoided if more information had been communicated to the family about the diagnosis.

After his son's experience, Col. Coffee became a very vocal patient advocate, serving as a member of his nearby PFAC and co-founding Patients for Patient Safety, US, an affiliate of the World Health Organization.



The diagnostic errors that I just shared could have been prevented. A national not-for-profit organization that collects and publishes patient safety and quality ratings for hospitals has convened a national advisory group and identified 29 things that hospitals can start doing now to reduce errors in diagnosis – including delayed, wrong, or missed diagnoses, and diagnoses not communicated to the patient.

One of the "recommended practices" – things that hospitals should do now to reduce errors in diagnosis – asks hospital leaders to establish goals for patient engagement, communication, and teamwork. These are three areas that researchers insist play a big role in reducing diagnostic errors.

As a PFAC, we can examine and discuss ways to partner with our hospital's leadership team around this recommended practice and others included in the report.

Understanding the Issues: Learning about the Diagnostic Process and Diagnostic Error

Discussion Questions

1. Based on what you've just learned and heard, do you think that you or anyone you know has experienced a diagnostic error?
2. If so, was the problem with the accuracy, timeliness, or communication of the diagnosis—or a combination of those issues?
3. If you do not think you or anyone who know has experienced a diagnostic error, have there been any "close calls" or times that something was *almost* missed?

Section 2

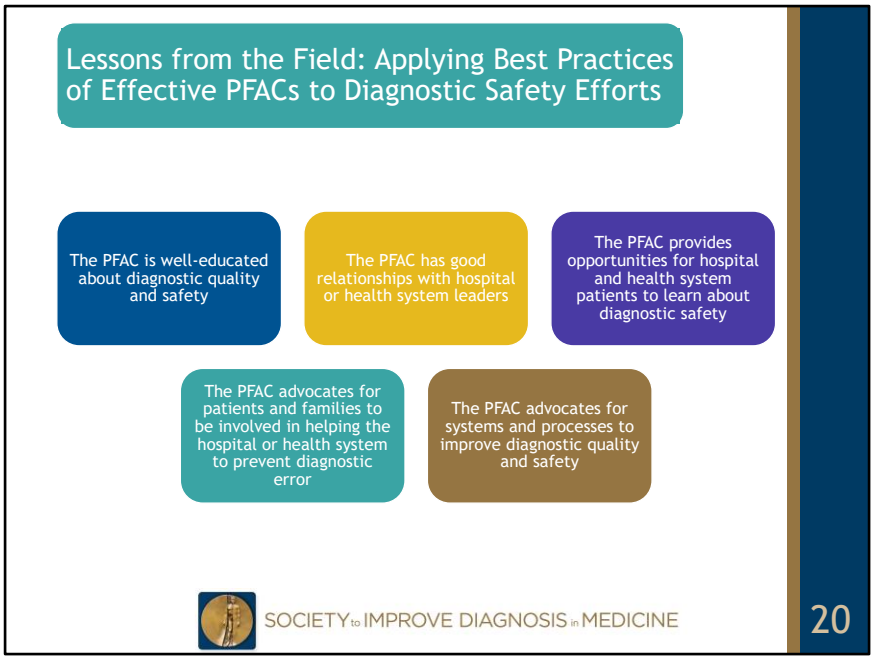
Lessons from the Field: Applying Best Practices of Effective PFACs to Diagnostic Safety Efforts

Lessons from the Field: Applying Best Practices of Effective PFACs to Diagnostic Safety Efforts

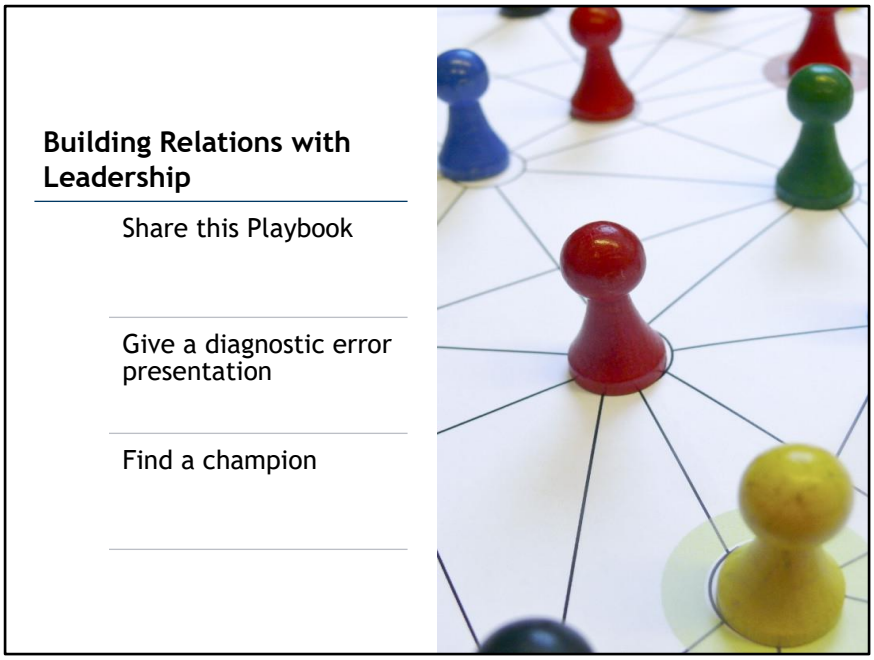
Effective PFACs have several common qualities that include (but are not limited to) the following:

- At least 50% of members are patient/family advisors reflecting diversity of community served
- Chair or co-chair is a patient/family advisor
- Have established guidelines (e.g., bylaws)
- Meet regularly (10-12 times per year)
- Provide orientation and ongoing training to members
- Seek a balance of PFAC-initiated and hospital staff-initiated projects
- Document impact of PFAC on safety and quality

(Institute for Patient and Family Centered Care PFAC resources, accessed August 9, 2022, https://www.ipfcc.org/bestpractices/sustainable-partnerships/engaging/effective-pfacs.html)

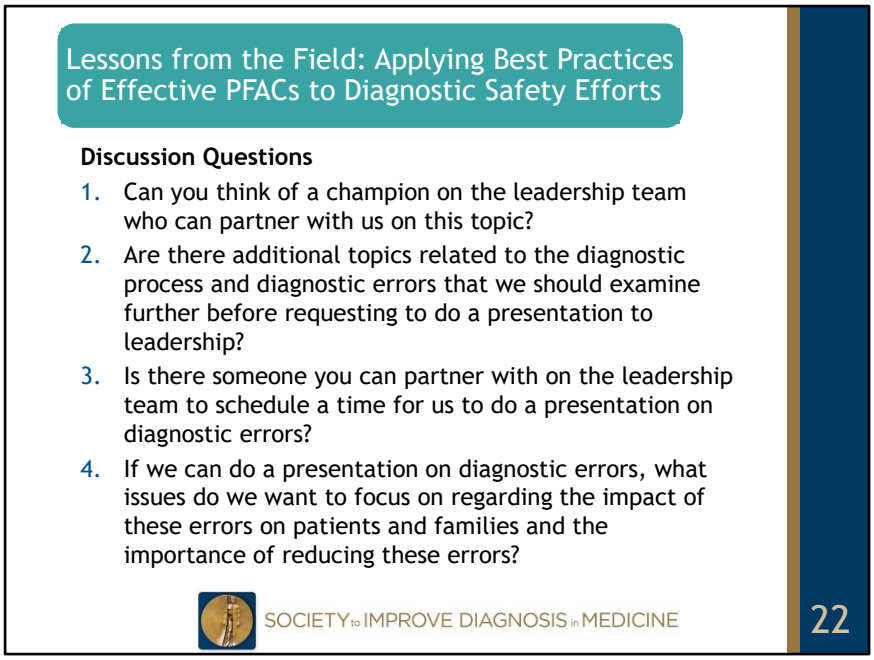


Here are some ways that other PFACs have been effective in addressing diagnostic errors. These examples come from SIDM.



As a PFAC, for us to be impactful on this topic, we must have effective communication with hospital leadership. Some ideas to accomplish this include:

1. Sharing this Playbook with hospital leadership and letting them know we are working our way through it over the next several meetings
2. Developing our own presentation on diagnostic errors to communicate why we think this is an important issue to address at our hospital
3. Identifying a champion on the leadership team to work with



Note: If your PFAC members want to learn more about the diagnostic process and/or diagnostic errors, refer to the resources listed in the Compendium of Resources that was sent out with this Playbook.

Section 3

Taking Action: Tackling Diagnostic Safety in Big and Small Ways

Taking Action: Tackling Diagnostic Safety in Big and Small Ways

Two "Types" of Engagement

Engaging patients and families to be actively involved in their own diagnostic process at the point of care

For example:
- Patient and care team have routine communication as test results come in

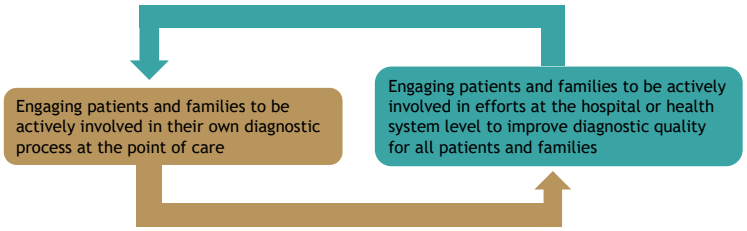
Engaging patients and families to be actively involved in efforts at the hospital or health system level to improve diagnostic quality for all patients and families

For example:
- PFAC members design materials for patients/families to keep track of tests being run and results coming in

Taking Action: Tackling Diagnostic Safety in Big and Small Ways

These two types of engagement are closely linked and PFACs have a role to play in both

By working with our hospital or health system to improve processes and practices and support a culture of safety…



…patients and families in the hospital or health system can more easily engage in their own diagnostic processes and navigate their care

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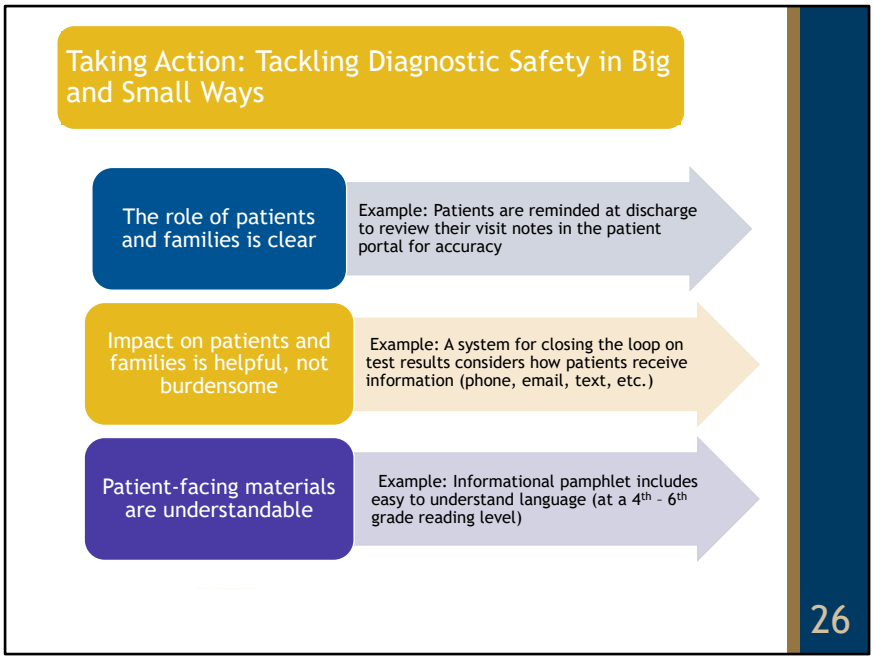


When we think about what big, or small ways, we want to be involved in reducing errors in diagnosis, including delayed, wrong, or missed diagnoses, and diagnoses not communicated to the patient, here are some principles we may want to remember:

1. The role of patients and families should be clear. For example, having accurate information about the health problem in the medical record helps ensure that patients receive an accurate diagnosis. While patients should review the notes the clinician took during the visit in the patient portal to ensure they are accurate, it would be more helpful if they were encouraged and prompted to do so at discharge by someone on the care team.
2. The impact on patients and families should be helpful, not burdensome. For example, not all patients may be able to easily access test results if they are only posted on the patient portal. Therefore, the notification of test results should consider all the ways that patients need to receive this information – including phone calls, text prompts, emails, etc.
3. Patient-facing materials should be easy to understand. For example, any materials that are designed for patients should be mindful that the average reading level is 4^{th} to 6^{th} grade

Taking Action: Tackling Diagnostic Safety in Big and Small Ways

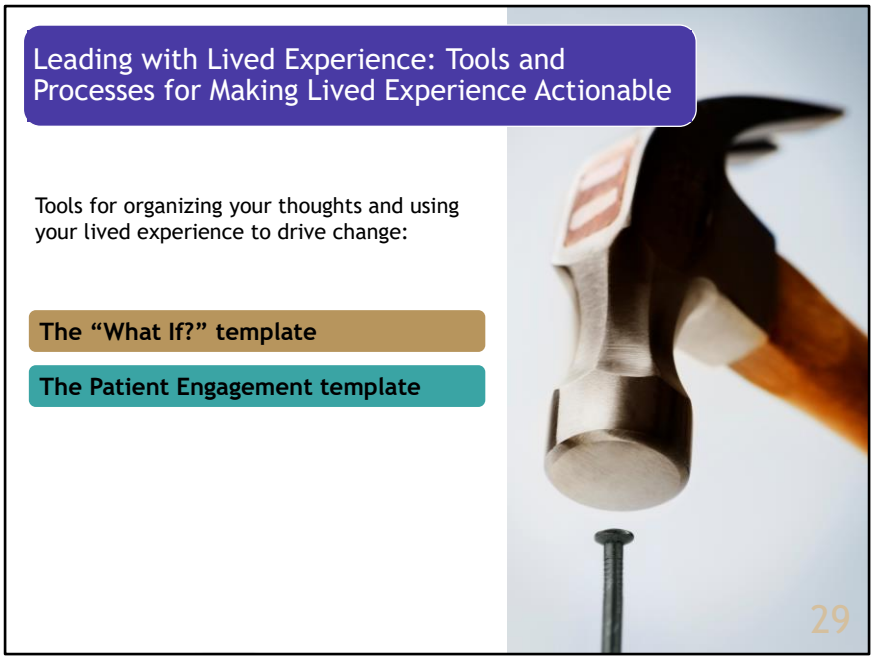
Discussion Questions

1. Are there any processes or practices at our hospital or health system that you think could be improved to reduce errors in diagnosis (including delayed, wrong, or missed diagnoses, and diagnoses not communicated to the patient)?

Section 4

Leading with Lived Experience: Tools and Processes for Making Lived Experience Actionable

The "What If" Template and Patient Engagement Template



For the past few meetings, we've been learning about and discussing the diagnostic process and diagnostic errors, and ways that we can reduce errors in diagnosis, including delayed, wrong, or missed diagnoses, and diagnoses not communicated to the patient. During this meeting, we are going to start putting those learnings and discussion into action.

We'll be reviewing the "What If" template and the Patient Engagement Template.

Three primary ways the lived experience of PFAC members can help address diagnostic errors:

The experience of a PFAC member drives an idea for an activity

Hospital or health system leadership has an idea and seeks Patient or Family Advisors with relevant lived experience

The lived experience of PFAC members can inform any initiative to reduce diagnostic errors, even if their lived experience is not specific to the topic

The "What If?" and Patient Engagement templates can help us get involved in all three ways.

1. The experience of a PFAC member drives an idea for an activity

The Patient Engagement template helps the PFAC map out an approach for partnering with the hospital/health system leadership to move the idea for the activity forward

The "What If?" template helps PFAC members reflect and get focused on specific aspects of an experience with a diagnostic error to identify specific potential activities and goals that would improve that experience (i.e., helps identify the idea for the activity)

2. Hospital or health system leadership has an idea and seeks Patient or Family Advisors with relevant lived experience

The "What If?" template helps PFAC members reflect and get focused on aspects of their experience **to contribute** to the project or idea at hand

The Patient Engagement template helps the hospital or health system leadership see how the PFAC and other Patient and Family Advisors can be partners

3. The lived experience of PFAC members can inform any initiative to reduce diagnostic errors, even if their lived experience is not specific to the topic

The "What If?" template helps PFAC members reflect and get focused on aspects of their experience that can be **generalized or applied to other scenarios**

The Patient Engagement template helps the PFAC and hospital or health system leadership collectively map out a plan to partner with each other

The What If? Template

The What If? Template is designed to leverage a patient's experience with diagnostic error to generate solutions.

The "What If?" approach prompts individuals to stop and think about "what if" scenarios that could have changed the outcome – prevented the diagnostic error - throughout the diagnostic process.

Asking "What If?" helps identify actions that your hospital can take to reduce or prevent patient harm from diagnostic errors.

"What If?" Template: Example

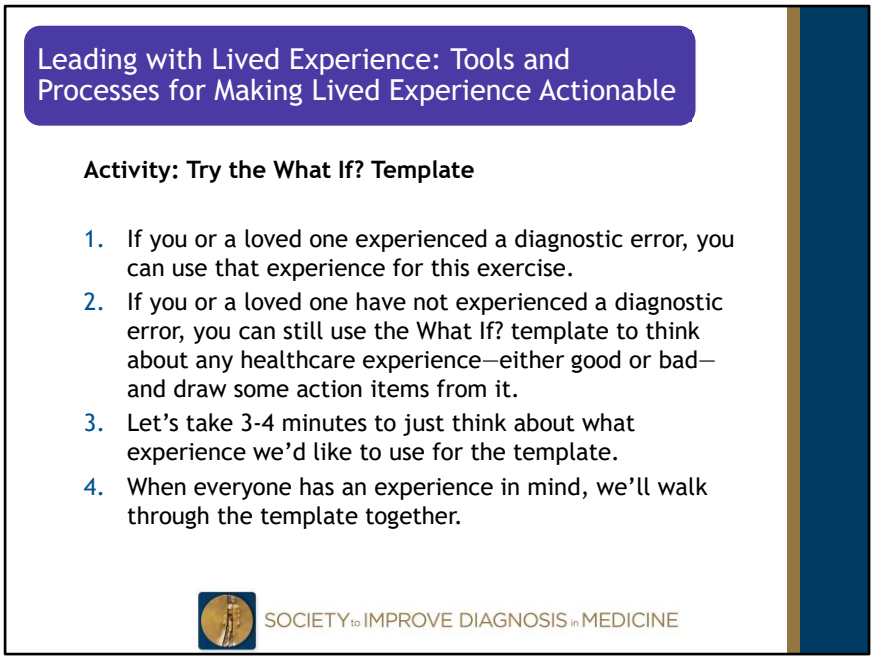
Introduction *Age, gender, other demographic characteristics of patient	Sally, 35 year old white female, just had a baby No personal medical history but family history of heart attacks in mother and sister
Background *How long had symptoms been going on and what were they? *What had been going on up to the point that this diagnostic error occurred? What were the healthcare interactions up to now?	All of a sudden started having chest pains and having trouble breathing Tried to take deep breaths and meditate but started to feel like I was going to pass out
Presentation *What happened when you arrived at the point of care? *What clinical information do you have from that time? • Vital signs? • Major symptoms? • History that you reported? • Anything else you can recall?	I went to the emergency room and explained my symptoms The triage nurse took my information and I was put in a room, I shared my family history I was given an EKG but it didn't show anything that made the doctor suspicious, so he suggested I was having a panic attack and he said it was common in "young women who are stretched too thin"
Hospital Course (if inpatient) or Course of Care/Treatment (if outpatient) • Tests or exams given? • Any provisional diagnoses suggested to you? • Any courses of treatment offered to you?	My symptoms continued to get worse while I was waiting in my room in the ER and I eventually lost consciousness I was not found for about 45 minutes and when I was found I had to be resuscitated
Ultimate (Correct)Diagnosis • What was it? • Who found it/identified it? • What damage, harm, or tragic outcome resulted?	I was ultimately diagnosed with Spontaneous Coronary Artery Dissection (SCAD) which, while rare, it most commonly happens during the third trimester or very soon after pregnancy
Discussion *Provide a few clinical details about the ultimate diagnosis, perhaps including statistics or other insight *Include any details you or family members noted as unusual or worrisome during the course of care/treatment (like "I kept mentioning that his lips looked bluish but none of the nurses were bothered by it" or "I reported that it was pain unlike anything I'd ever felt before but they kept saying it was normal post-surgical pain")	I remember being confused by the working diagnosis of a panic attack because I wasn't feeling anxious (other than concern about my chest pain and inability to breathe) I also reported that I had just had a baby, but since this was a different hospital, I wasn't in their system and I kept having to repeat that part every time a new doctor or nurse came in
Teaching points/Opportunities to Improve *What were the breakdowns that, had they not happened, or happened differently, the error or resulting harm could have been avoided—the "What Ifs"? *What can be learned from your experience? *What do you want clinicians/hospitals/other stakeholders to take away from what happened to you?	- There is too little education focused on the cardiovascular risks during and immediately after pregnancy; we need co-located Ob/Gyn and Cardiovascular training - EKGs may not show SCAD; they should not be the exclusive diagnostic test for a post-partum woman showing up with heart attack symptoms - Each patient needs to be evaluated independently and not be given diagnoses because they fit a certain "type"; I wasn't exhibiting key signs of a panic attack

Note: Starting with the introduction, read aloud the header and text under the header in the left column of the table. Then move to the right column of the table and read the example.

- "Let's start with an introduction to the patient, including the patient's age, gender, and any other important characteristics - Sally is a 35 year old white female who just had a baby. She has no personal medical history, but she has important family history: her mother and sister both had a heart attack."

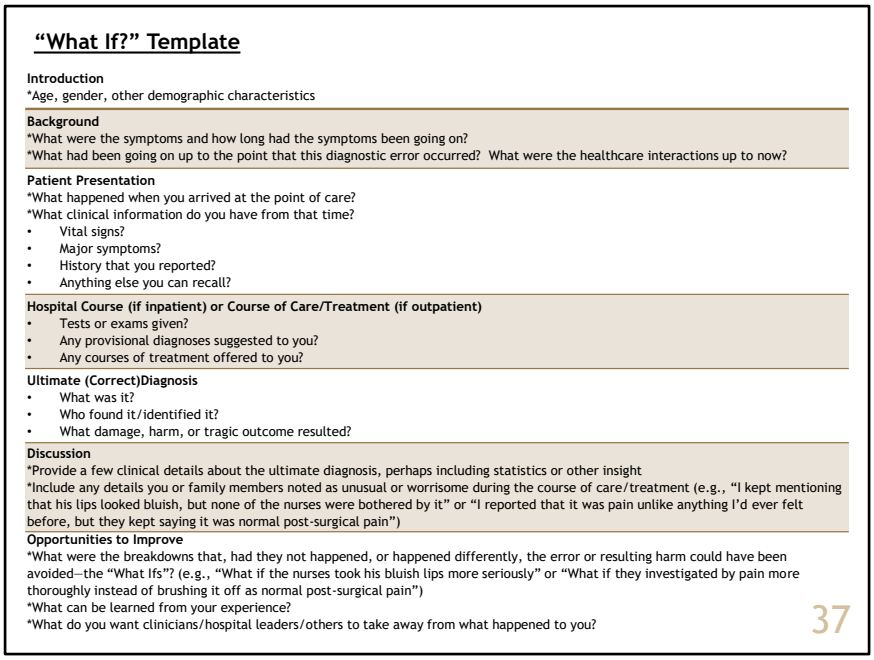
- "Now let's move on to the background on the patient's health problem, including the symptoms, how long the symptoms had been going on, and any other important information leading up to this, including interactions with other healthcare providers – Sally suddenly started having chest pains and trouble breathing. She tried to take deep breathes and meditated but started feeling like she was going to pass out."

Use the scripted language examples above to review the entire template.



Now we are going to complete the What If? Template for ourselves. Here are some options to help you pick an experience for the template exercise.

Note: Read examples directly from the slide.



Now that everyone has an experience in mind, let's go through the template. I'm going to read the questions as if they apply to "you" rather than "you or a loved one" for ease of the exercise, but of course, if the experience you have in mind is that of a loved one, please jot down your responses accordingly.

Note: Read aloud each header and list of questions under each header and ask your PFAC members to jot down answers to each question as you move through the template. Be sure to pause after each set of questions to allow members time to process and respond.

The Patient Engagement Template

The Patient Engagement Template is also designed to ensure that patients and their lived experiences are at the center of efforts to reduce or prevent harm to patients from diagnostic errors.

The template includes three important stages of process improvement: planning, conducting, and dissemination, and identifies opportunities at each of the three stages to involve patients.

Using the Patient Engagement Template helps ensure that patient experiences are leveraged to improve hospital processes.

Patient Engagement Template Example:

Creating a patient and family-accessible pathway for escalating care (e.g., getting a patient a higher level of care, such as moving them from a medical unit to a critical care unit, if the patient's condition is deteriorating)

Patient Engagement Considerations	Your Plan
Planning • What is the profile of patient or caregiver necessary for this role? • If not already on your PFAC, how can you identify additional partners? • Are there other patient safety groups in your area who may be helpful? • How can the patients partner in the creation and design of the plan for the project/effort?	• Patients/caregivers who have had to escalate an emergent issue, or have similar experience with advocating for increased attention or awareness • Recruit from patient members of local patient safety authority • Identify the major "What ifs" from their diagnostic breakdown and what a valid escalation pathway would look like
Conduct • How can patient partners co-design specific elements of the intervention (i.e., data collection tools and processes) • As results emerge, how can patient partners help to prioritize meaningful themes and trends, and help to interpret findings? • How can patients partner in ongoing assessment and adjustment of the project/effort?	• Design the pathway to reduce intimidation, eliminate fear of retribution or poorer care, ensure access to the pathway is widely known to patients • As the process is being tested, review demographics and characteristics of "users" and identify gaps—are there people this process isn't reaching? Are revisions needed? • Suggest anonymous input from patient users, design simple surveys to capture that input, and contribute to analysis
Dissemination and/or Evaluation • How can the patient partners help to identify and participate in unique and patient-relevant venues for dissemination? • How can patients partner in evaluation and improvement of the project/effort?	• If this is a successful project, present at another convening of fellow PFACs • Continue or build up on the assessment designed above—anonymous survey, identify other sources of patient input

Adapted from the SIDM CER Toolkit, Patient Engagement in Diagnostic Quality Research, A Step-by-Step Guide, Patient-Centered Outcomes Research Institute® (PCORI®) Engagement Award Initiative (EAIN-00009), accessed at: https://www.improvediagnosis.org/researcher-toolkit/

Note: Starting with the Patient Engagement Considerations column (left column), read aloud the header and text under the header. Then move to the Your Plan column (right column) of the table and read the example aloud.

- "Let's start with the planning elements for this example activity, which is to create a patient and family-accessible pathway for escalating care.

  Escalating care means that the care team responds to patient or family requests to get the patient a higher level of care as soon as possible – such as moving a patient from a medical unit to a critical care unit due to a patient's rapidly deteriorating condition.

  To start planning, the PFAC needs to identify the patient or caregiver needed and if not already represented on the PFAC, where we could recruit them. In addition, the PFAC needs to consider how the patient or caregiver can partner in the design pathway for escalating care.

  In this example, the PFAC needs to find patients or caregivers who have had the experience of escalating care in a hospital and get their input on what a formal

process or pathway might look like that all patients and families can access."

Use the scripted language example above to review the entire template.

Leading with Lived Experience: Tools and Processes for Making Lived Experience Actionable

Activity: Try the Patient Engagement Template

1. This tool is more for planning out an action you want to take as a PFAC so it might b easiest to use it once you have decided on an idea to pursue
2. Just to get familiar with the tool, we'll walk through the sections and see an example of what a completed template would look like
3. Whenever we are ready to come together to work on a project or activity, we can use the template to pull our thoughts and ideas together

SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

PFAC Template for Patient Engagement in Diagnostic Quality Improvement

Patient Engagement Considerations	Your Plan
Planning • What is the profile of patient or caregiver necessary for this role? • If not already on your PFAC, how can you identify additional partners? • Are there other patient safety groups in your area who may be helpful? • How can the patients partner in the creation and design of the plan for the project/effort?	
Conduct • How can patient partners co-design specific elements of the intervention (i.e., data collection tools and processes) • As results emerge, how can patient partners help to prioritize meaningful themes and trends, and help to interpret findings? • How can patients partner in ongoing assessment and adjustment of the project/effort?	
Dissemination and/or Evaluation • How can the patient partners help to identify and participate in unique and patient-relevant venues for dissemination? • How can patients partner in evaluation and improvement of the project/effort?	

Adapted from the SIDM CER Toolkit, Patient Engagement in Diagnostic Quality Research, A Step-by-Step Guide, Patient-Centered Outcomes Research Institute® (PCORI®) Engagement Award Initiative (EAIN-00009), accessed at: https://www.improvediagnosis.org/researcher-toolkit/