SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

Tackling Diagnostic Error in Your Hospital

A Playbook for your PFAC

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/.

SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

Playbook Description

This Playbook is designed for use by a hospital's PFAC. The goal of the Playbook is to help PFACs determine their knowledge and readiness to reduce diagnostic errors through education, discussion questions, and a couple activities. This template includes the same information as the Playbook Facilitator's Guide but does not have any talking points. This presentation should be delivered by a PFAC leader.

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A Playbook for PFACs

Playbook Sections

1.) Understanding the Issues: Learning about the Diagnostic Process and Diagnostic Error

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

3.) Taking Action: Tackling Diagnostic Safety in Big and Small Ways

4.) Leading with Lived Experience: Tools and Processes for Making Lived Experience Actionable

- "What if" Template
- Patient Engagement Template

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**

SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

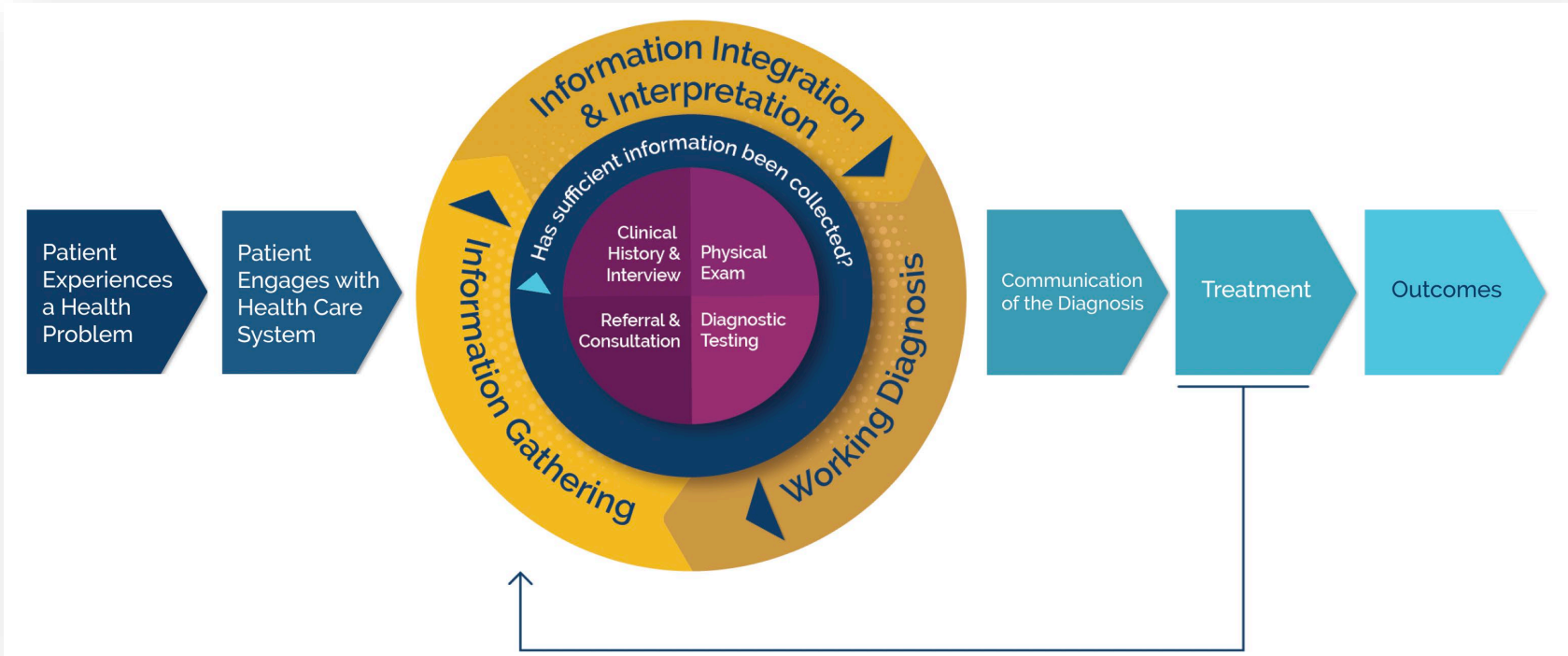
Understanding the Issues: Learning about the Diagnostic Process and Diagnostic Error

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.

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



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

Accurate

Timely

Communicated

Accurate

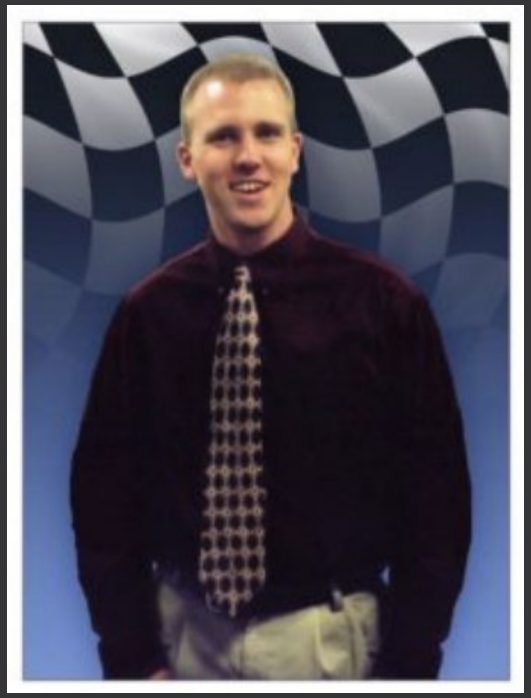
The Missed Test
Julia Berg's Story
Minneapolis, MN

Julia Berg

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.

Timely

Tested Too Late
Chad Becken's Story
Burbank, CA



Chad Becken was a 36-year-old man working in payroll in the entertainment industry in Burbank, CA, when he began having strange symptoms in early 2010. Chad was experiencing lower back pain, fatigue, frequent bowel movements, and weight loss. He had visited his primary care physician twice and had gone to Urgent Care once when he finally came to his mom for advice.

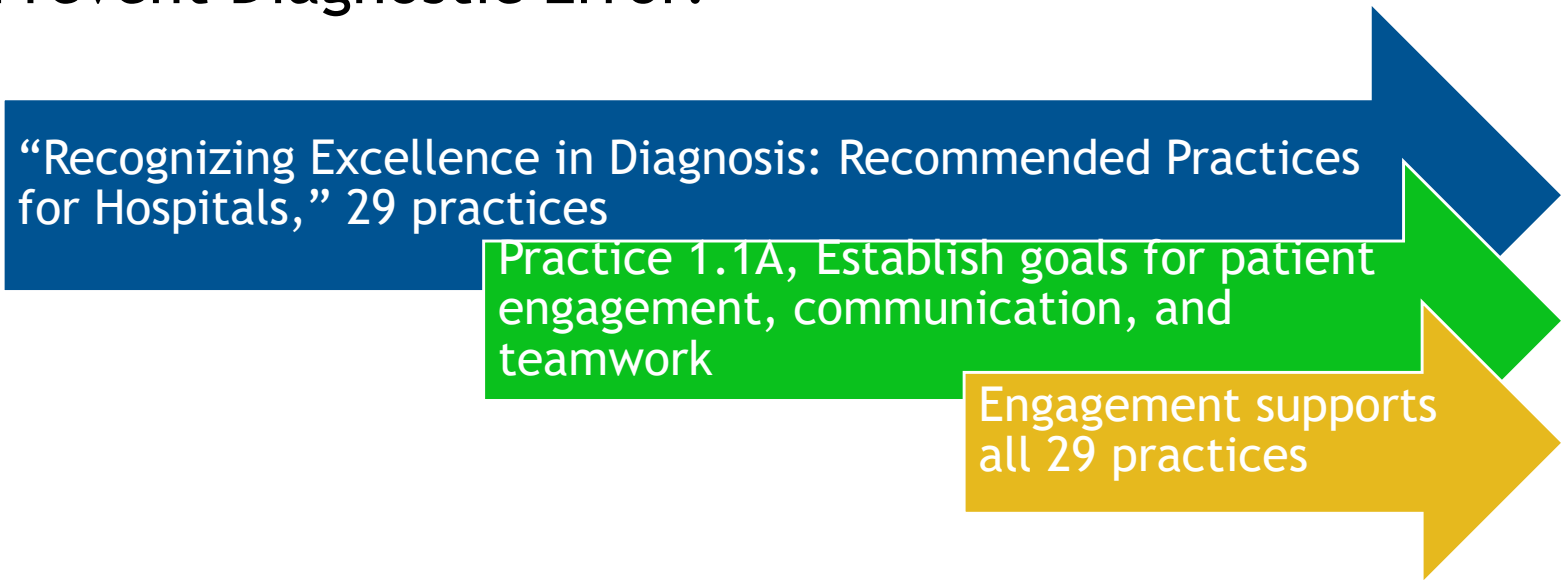
Communicated

Failed to Communicate Steven Coffee II's story Hampton, VA

Steven Coffee II was born prematurely on September 28, 2012 to two excited new parents living in Hampton, Virginia. Initially, Steven had low glucose levels, high bilirubin levels, and threw up milk. Although the nervous, first-time parents were concerned, they were told it was not too alarming because Steven was born at 37 weeks and six days. What Lt. Col. Steven Coffee didn't know was that his son was showing telltale signs that something was seriously wrong.

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

How can Hospitals and Health Systems Prevent Diagnostic Error?



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)

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

The PFAC is well-educated about diagnostic quality and safety

The PFAC has good relationships with hospital or health system leaders

The PFAC provides opportunities for hospital and health system patients to learn about diagnostic safety

The PFAC advocates for patients and families to be involved in helping the hospital or health system to prevent diagnostic error

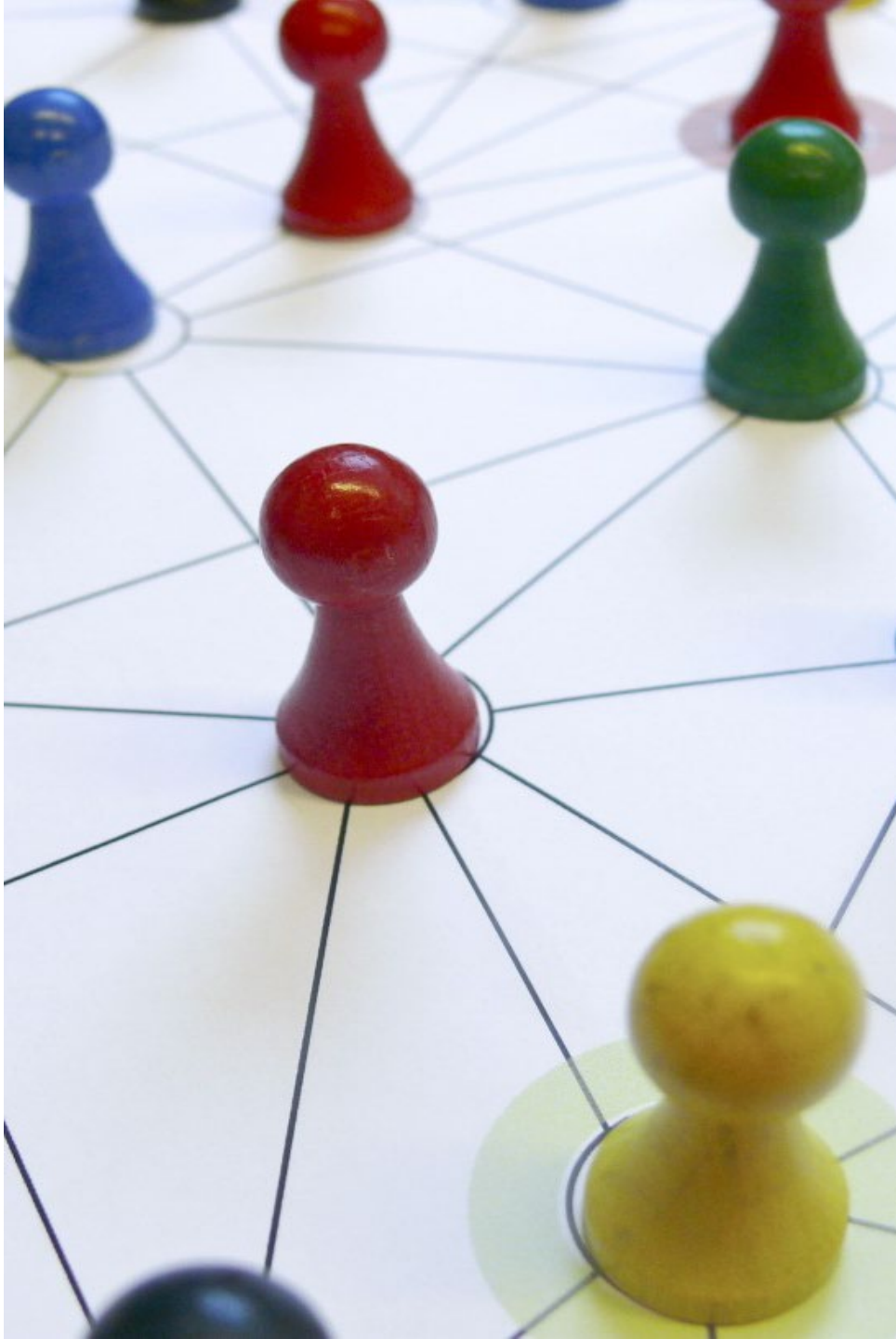
The PFAC advocates for systems and processes to improve diagnostic quality and safety

Building Relations with Leadership

Share this Playbook

Give a diagnostic error presentation

Find a champion



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

Discussion Questions

1. Can you think of a champion on the leadership team who can partner with us on this topic?
2. Are there additional topics related to the diagnostic process and diagnostic errors that we should examine further before requesting to do a presentation to leadership?
3. Is there someone you can partner with on the leadership team to schedule a time for us to do a presentation on diagnostic errors?
4. If we can do a presentation on diagnostic errors, what issues do we want to focus on regarding the impact of these errors on patients and families and the importance of reducing these errors?

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

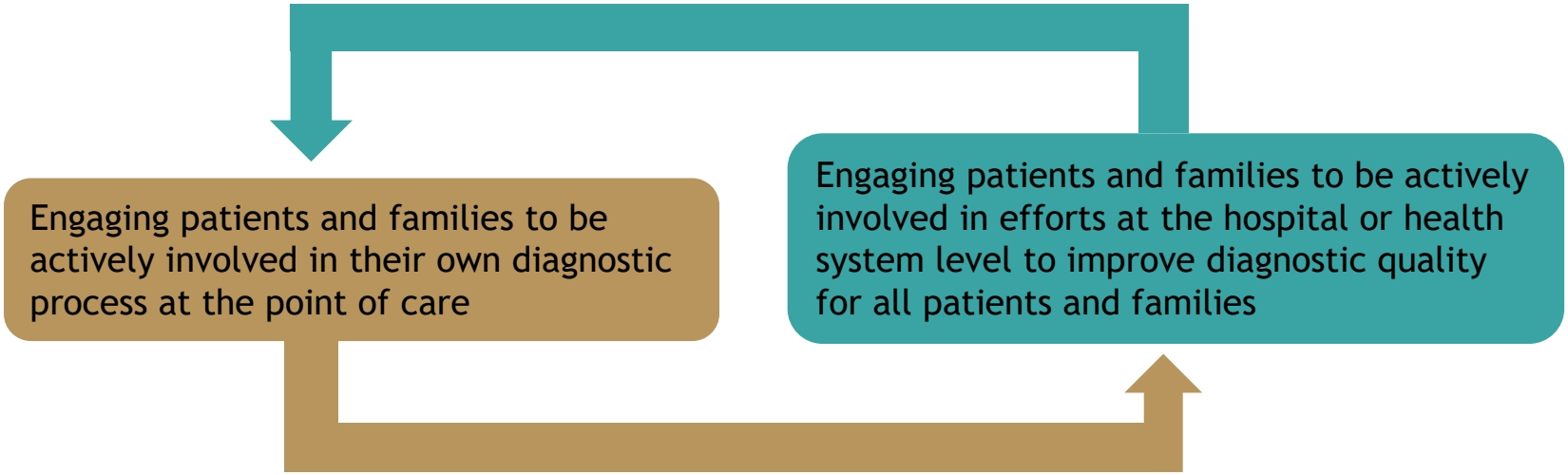
For example:

- 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

Taking Action: Tackling Diagnostic Safety in Big and Small Ways

The role of patients and families is clear	Example: Patients are reminded at discharge to review their visit notes in the patient portal for accuracy
Impact on patients and families is helpful, not burdensome	Example: A system for closing the loop on test results considers how patients receive information (phone, email, text, etc.)
Patient-facing materials are understandable	Example: Informational pamphlet includes easy to understand language (at a 4th – 6th grade reading level)

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

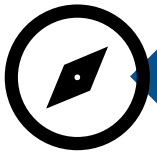
Leading with Lived Experience: Tools and Processes for Making Lived Experience Actionable

Tools for organizing your thoughts and using your lived experience to drive change:

The "What If?" template

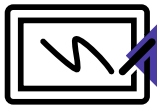
The Patient Engagement template

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

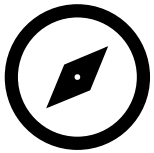
The "What If?" and Patient Engagement templates can help us get involved in all three ways.

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)

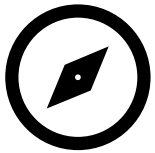
2. Hospital or health system leadership has an idea and seeks Patient or Family Advisors with relevant lived experience



The "What If?" template helps PFAC members reflect and get focused on aspects of their experience **<u>to contribute</u>** 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

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

Activity: Try the What If? Template

1. If you or a loved one experienced a diagnostic error, you can use that experience for this exercise.
2. If you or a loved one have not experienced a diagnostic error, you can still use the What If? template to think about any healthcare experience—either good or bad—and draw some action items from it.
3. Let's take 3-4 minutes to just think about what experience we'd like to use for the template.
4. When everyone has an experience in mind, we'll walk through the template together.

“What If?” Template

Introduction
*Age, gender, other demographic characteristics

Background
*What were the symptoms and how long had the symptoms been going on?
*What had been going on up to the point that this diagnostic error occurred? What were the healthcare interactions up to now?

Patient 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?

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?

Ultimate (Correct)Diagnosis
- What was it?
- Who found it/identified it?
- What damage, harm, or tragic outcome resulted?

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 (e.g., “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”)

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”? (e.g., “What if the nurses took his bluish lips more seriously” or “What if they investigated by pain more thoroughly instead of brushing it off as normal post-surgical pain”)
*What can be learned from your experience?
*What do you want clinicians/hospital leaders/others to take away from what happened to you?

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/

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

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?	
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