



PFAC Toolkit for Exploring Diagnostic Quality **Facilitator Guide**

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MEDICINE

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Introduction and Purpose of the Toolkit

Welcome to the Facilitator’s Guide for the Patient and Family Advisory Council (PFAC) Toolkit for Exploring Diagnostic Quality! This Toolkit was created as part of the Leapfrog Group’s [“Recognizing Excellence in Diagnosis: Recommended Practices for Hospitals”](#) project. The meaningful engagement of patients and families is one of the recommended practices, and this Toolkit was designed to help hospital PFACs learn about diagnosis, diagnostic quality, and explore ways to reduce diagnostic error in their institutions. The Toolkit includes foundational information about diagnostic safety and patient engagement methodology, and provides exercises and guidance for fighting back against diagnostic error in the hospital setting. When your PFAC has completed all of the sections, they will have in hand, a draft project or activity plan to tackle diagnostic error at your institution.



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Your Role as a PFAC Facilitator or Leader

As the leader or facilitator of your PFAC, you have an important role to play in the administration of this Toolkit. Even though these resources are meant to be interactive and all members of your PFAC should be involved in the discussions and exercises, you will be keeping the group on target and moving forward through the sections and activities. You will also be working to build or strengthen your PFAC's relationships with hospital leadership and those tasked with safety and risk in your organization. Those relationships will be an important factor in your PFAC's ability to move forward on a project or activity. If you do not already have established relationships, resources from the Toolkit can help build or strengthen those relationships with diagnostic safety and quality leaders.

Some of the discussions and exercises will be focused on the lived experience of your PFAC members, including opportunities to share their own experiences with diagnostic errors or other notable medical events. Please stress to your PFAC members that how much they share and exactly what they choose to share is completely voluntary; they are not required to share any personal stories or perspectives if they do not wish to. It is also valuable to reinforce to your PFAC members that while it is often stories of harm or "what went wrong" that are used in diagnostic quality work, stories of what went "right" are just as valuable, and PFAC members should feel comfortable sharing whatever medical or clinical experiences they feel are relevant.

You set the tone and energy for the discussions and activities. An environment that is welcoming and responsive to comments can make everyone feel safe. Try to be equally enthusiastic or supportive of all comments and ideas to avoid the perception that some ideas or comments are better than others. That said, there may times when a suggestion or idea is off-base and you may need to respectfully and politely explain or reframe the issue (see example below). Other times an idea or suggestion may be a great concept, but one that is out of scope for this Toolkit. In those cases, keeping a "parking lot" of good ideas is a helpful way to acknowledge and keep track of those suggestions should there be opportunities outside of this setting to develop the concepts further. In Section 6, you will use and share tools to identify what project or activity ideas are most probable and/or likely to succeed, and which are less so. You will also use and share methods for coming to a consensus—or close to a consensus—about what project or activity idea the group should tackle first.

The goal of this Toolkit is to promote learning and awareness, and ultimately for your PFAC to identify a potential project or activity in diagnostic quality that you may want to address. It is important that the tone of the discussions and exercises is positive and forward-looking. It can be easy to fall into the habit of focusing on what is not working or what has gone wrong, and while sharing those stories can be valuable, your role as the facilitator will be to move the group from "what went wrong" to "what are we going to do about it".

Along these same lines, encourage your PFAC members to never disclose the names of individual clinicians or institutions when sharing stories about their care. If a family member or caregiver on your PFAC is sharing personal stories or information, make sure they disclose that they have gained permission from the patient before sharing, and that they never use the full name of the patient. Individual PFAC members who have had an experience with diagnostic or other medical error that resulted in harm may also need to check to make sure they are not under any type of legal "gag order" that prevents them from sharing their lived experience.



Your Role as a PFAC Facilitator or Leader, (cont'd)

Respectful Content Correction

Brainstorming and group discussions can be productive and energizing activities, but they do require facilitation, and in some cases, you may need to gently guide the conversation toward a goal, or away from an unhelpful or irrelevant topic.

Scenario: Someone offers an idea that is based on a mistake or misunderstanding.

Your role: Gently correct and refocus in the moment. Regardless of the exact issue, the approach is the same.

- Start with gratitude and acknowledgement.
- Consider that there may have been misinterpretation or that the speaker was sharing the piece of information not because he or she believes it to be true, but to make everyone aware that the belief exists.
- Respectfully inquire and/or offer alternative explanation.
- Ask for guidance on how to use/be responsive to the issue or some component of the issue and refocus the idea.

Example: A PFAC member suggests that as a potential project, the PFAC could develop educational materials for patients in the emergency room. They want to let patients know that whenever their blood is drawn for diagnostic testing, some of it is saved and used for research without their consent.

- Start with gratitude and acknowledgement:
 - “Thank you so much for sharing that idea and sharing your concerns about this issue with us!”
- Consider that there may have been misinterpretation or that the speaker was sharing the piece of information not because he or she believes it to be true, but to make everyone aware that the belief exists:
 - “I’d like to dig in a little deeper and understand more about this issue; is this something you’ve experienced?”
- Respectfully inquire and/or offer alternative explanation:
 - “So, while that is a great idea, this practice is not something we do here at our hospital; we can only take samples for research purposes if we have gotten informed consent beforehand. But, if this is something that is worrisome to you, I’m happy to talk it through with you.”
- Ask for guidance on how to use/be responsive to the issue or some component of the issue and refocus the idea:
 - “Maybe since this isn’t an issue at this hospital, but it may be a concern of patients who have been treated at other hospitals, we could develop educational materials about informed consent in general to help them understand that if they are invited to contribute to research they should feel empowered to read and ask questions about the materials provided and that they are under no obligation to say yes.”

Toolkit Components and Cadence

The entire package of materials is called the PFAC Toolkit. The Toolkit includes six modules to review and discuss with your PFAC, and the sections incorporate group exercises, instructional videos, and interactive templates. There are Supplemental Materials and information available if needed, hyperlinked from the main Toolkit webpage. The timing and cadence of the sections is somewhat dependent on how your particular hospital and PFAC operate (i.e., how often you meet, how long your meetings are, etc.). In general, you should aim to cover 1-2 sections of the Toolkit per PFAC meeting, over the course of an hour or two. The materials can be used either in person or virtually, and with slight modifications in your guidance depending on whether you are meeting in person or virtually.

Suggested Cadence

<p>Meeting 1</p>	<p>Section 1. Introduction and How to Use this Toolkit</p> <ul style="list-style-type: none"> • Part One: What are the Pieces of the Toolkit and How do We Use Them_Video (Shown to the PFAC live or virtually.) • Part Two: Overview of Sections and Materials (Presented by the facilitator live or virtually) <p>Section 2. Introduction to Patient and Family Engagement</p> <ul style="list-style-type: none"> • Part One: What is it, how does it work, and why is it so important? (Presented by facilitator live or virtually, several group discussions and opportunities to share.) • Part Two: The Role of Patient and Family Advisory Councils (Presented by facilitator live or virtually, examples of PFACs doing meaningful engagement, several group discussions and opportunities to share.)
<p>Meeting 2</p>	<p>Section 3. Understanding the Diagnostic Process and Diagnostic Safety</p> <ul style="list-style-type: none"> • Part One: Diagnosis and the Diagnostic Process (Presented by facilitator live or virtually, involves discussion, brainstorming, and sharing.) • Part Two: Introduction to Diagnostic Error (Presented by facilitator live or virtually, involves discussion, brainstorming, and sharing.) <p>Section 4. Diagnosis and You</p> <ul style="list-style-type: none"> • Part One: Learning from Diagnostic Experiences (Presented by facilitator live or virtually, includes description/discussion of using stories of diagnostic error as learning/teaching opportunities, introduction of the “What if?” Template, everyone is facilitated to use the template to describe a diagnostic experience, negative or positive.) • Part Two: Using the “What if?” Template Video (This is shown to the PFAC in the middle of Part One, and before the group works through the “What if?” Template exercise together.) • Tool: What if? Template (Available in the Supplemental Materials.)
<p>Meeting 3</p>	<p>Section 5. What could we do about diagnostic quality at our institution?</p> <ul style="list-style-type: none"> • Part One (only part in this section): What could we do about diagnostic quality at our institution? (Presented by facilitator live or virtually, discuss need for relationship with hospital leadership, examples of what PFACs have done, and what your PFAC can do.) • Tool: Template Letter for Hospital Leadership • Tool: Template Deck for Meeting with Hospital Leadership

Suggested Cadence, (cont'd)

Meeting 4	Meeting with hospital leadership, using the Template Deck for Meeting with Hospital Leadership from Section 5, to discuss diagnostic quality activities going on in the hospital and opportunities for projects or activities
Meeting 5	<p>Section 6. Getting Practical</p> <ul style="list-style-type: none">• Part One: How can our PFAC partner in diagnostic quality and safety activities? (Presented by facilitator live or virtually, includes a quick refresh of the What if? Template, introduction to using the Project Plan Template, introduction to Patient Engagement Template, and a group exercise to populate the Patient Engagement Template)• Part Two: Finding our project! (Presented by facilitator, group organizes around a project idea or ideas and begins to sketch out a project plan.)• Tool: Patient Engagement Template• Tool: Project Plan Template• Tool: Multi-voting Guidance• Tool: Evaluating Impact and Difficulty Matrix

***If necessary, the meeting with hospital leadership to discuss diagnostic quality and potential ideas for projects or activities can happen after you work through Section 6. It just depends on what works best at your institution. Because you'll be developing a draft project plan as part of Section 6 activities, you may just need to update or revise accordingly based on what you learn and discuss with leadership.**



Logistics, Guidance, and Suggested Script for Each Section of the Toolkit

If your PFAC meets virtually, you will need to broadcast each slide deck through Zoom or another virtual platform so that the group can see the slides as you walk through the content. If your PFAC meets in person, you will need to have a projector and screen set up in the room where the meeting occurs so that everyone can see the slides as you walk through the content.

There are many interactive discussions throughout the Toolkit Sections, and in many cases you will need to capture the ideas and comments in a way that is visible to everyone. For in-person meetings, this can be a flip-chart, whiteboard, chalkboard, or something similar. For virtual meetings, you can add a blank slide to the slide deck you're showing and capture notes and thoughts in real time. To add a blank slide, you'll need to show the slides in "edit" mode rather than "presentation" mode.

There are also Sections with exercises and templates. For in-person meetings, you will want to print hard copies of the templates. For virtual meetings, you may want to encourage your PFAC members to print the templates at home (if possible), or to have them downloaded onto their PC or iPad. Alternatively, you may consider printing and mailing templates to your PFAC members in advance.

To help you lead your PFAC through the Toolkit materials, we have provided guidance and suggested scripting for each Section of the Toolkit that has a corresponding PowerPoint. To differentiate between facilitator guidance and script language, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language to use, please feel free to be conversational and paraphrase as needed.



Section 1. Introduction and How to Use This Toolkit

Part One of Section 1, *What are the Pieces of the Toolkit and How do We Use Them?* is a video, and after a brief welcome and introduction (below), you will play the video for the group either projected to a screen if you meet in-person, or using Zoom or another meeting platform if you meet virtually. The video introduces the goals for the Toolkit, and provides a high level overview of the pieces of the Toolkit and how it is meant to be used. In Part Two of Section 1, *Overview of Sections and Materials* you will go into much more detail about each section and get the group excited and ready to start working through the Toolkit.

Section 1. Part One: Introduction and How to Use this Toolkit - What are the Pieces of the Toolkit and How do We Use Them?_(Video)

After your normal welcome or any other activities you need to take care of at the beginning of the meeting, you will introduce the first section of the Toolkit.

- Prior to playing the video, say:
 - Today we are excited to begin the PFAC Toolkit for Exploring Diagnostic Quality! Our first step is to watch an introductory video—this is Part One of Section 1, titled What are the Pieces of the Toolkit and How do We Use Them?

- Play the video, and after the video concludes continue with the guidance below.
 - Pause for any questions or comments about the video before moving on to Part Two.
 - Let’s pause here for questions. Are there any questions about the video? We will cover the pieces of the Toolkit in much more detail in the next part of this Section, but I am happy to answer any questions first.
 - Pause for questions and comments for 2-3 minutes, and then when conversation has ended or when 2-3 minutes have passed, indicate that you are going to move on to Part Two.

Section 1. Part Two: Introduction and How to Use this Toolkit - Overview of Sections and Materials

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language, please feel free to be conversational and paraphrase as needed.

In Part Two: *Overview of Sections and Materials*, you will be walking through content with occasional pauses for questions or discussions. This portion of the Toolkit is meant to go pretty quickly, so that you can move into Section 2 and begin to roll your sleeves up and get to work.

- Slide 1
 - We just finished watching the introductory video which described all of the pieces of the Toolkit, and now we are moving on to Part Two of Section 1, to do a deeper dive into these materials and learn about what we’ll be doing as we work through the sections

Section 1. Part Two: Introduction and How to Use this Toolkit - Overview of Sections and Materials, (cont'd)

- Slide 2
 - It might be helpful to think about the content in terms of what the goals are for the various components.
 - As you know, the Six Sections cover content, exercises, and templates.
 - The supplemental materials provide examples of PFAC efforts in diagnostic quality, and resources on diagnostic quality and safety, and patient and family engagement.
 - But all of this information is provided so that PFACs—all of us here—can learn about diagnostic quality, practice and sharpen our skills, and ultimately identify a project or opportunity to shape diagnostic quality here at our hospital. Ultimately, the purpose of this toolkit is to leverage patient experience with the health care system to help hospitals reduce errors in diagnosis.
- Slide 3
 - On the screen are the six sections, and each one has specific goals and activities. First is this introductory section which we are currently working through, so we will start our review with section 2, Introduction to Patient and Family Engagement.
- Slide 4
 - Section 2 has two parts—each in a slide deck.
 - Part One, *What is it, how does it work, and why is it so important?*, explains what patient and family engagement is, how it works, and why it matters. There are several group discussions and opportunities to share your experiences with engagement.
 - Part Two, *The Role of Patient and Family Advisory Councils*, explains the qualities of highly effective PFACs, provides examples of PFACs who are doing meaningful work in diagnostic quality, and will ask us to reflect on our work as a PFAC—thinking about our accomplishments as well as where we want to go from here.
- Slide 5
 - Next is Section 3, *Understanding the Diagnostic Process and Diagnostic Safety* also has two parts—each with a slide deck.
 - Part One, *Diagnosis and the Diagnostic Process*, covers the basics of diagnosis, and how to use the diagnostic process map (which you will learn about later). We will walk through, learn and discuss each step of the long and complicated process of diagnosis. That deck ends with an explanation and discussion of some of the key “drivers” or factors that lead to diagnostic quality.
 - Part Two, *Introduction to Diagnostic Error*, covers the basics of diagnostic error including the definition, the prevalence of errors, common types of error, and real-life stories from families affected by—and harmed by—diagnostic error.



Section 1. Part Two: Introduction and How to Use this Toolkit - Overview of Sections and Materials, (cont'd)

- (Slide 5, cont'd) The deck ends with an example of a currently available tool to support patients and families in the diagnostic process—the Society to Improve Diagnosis in Medicine’s Patient Toolkit for Diagnosis.
- We’ve covered quite a bit of content so let’s pause for a minute to see if anyone has questions.
- Pause for 3-4 minutes to take any questions or comments, then move on to slide 6.
- Slide 6
 - Section 4, *Diagnosis and You*, has three component pieces.
 - Part One, *Learning from Diagnostic Experiences*, is a slide deck that talks about the practice of using stories of diagnostic error—or success—as learning or teaching opportunities, by working through a tool called the “What if” template.
 - Part Two, *Using the What If? Template*, is a brief video tutorial that describes how to use the What If? template.
 - And finally, each of us will be guided through an exercise using the What If? template to describe one of our own diagnostic experiences, and identify opportunities for learning or improvement from that experience.
- Slide 7
 - Section 5, *What could we do about diagnostic quality at our hospital?*, has three components; a slide deck, a letter template, and a meeting with hospital leadership.
 - However, there is only one “part” in this Section, which is a slide deck that focuses on the need for a strong relationship between the PFAC and hospital leadership. The deck also provides examples of what other PFACs have done to address diagnostic quality in their hospitals and provides ideas for how to identify projects in diagnostic quality for us to take on.
 - This section also includes a template to use for a letter (or email) to reach out to leadership and invite them to a meeting to discuss our interest in diagnostic quality; it also includes a template for a slide deck that we can use for a meeting with hospital leadership.
 - Around the time when we cover Sections 5 and 6, we will have a meeting with hospital leadership and other relevant hospital team members, timing will be depending on availability. Talking with leadership will be an important part of planning and preparing to start a diagnostic quality project at our hospital.

Section 1. Part Two: Introduction and How to Use this Toolkit - Overview of Sections and Materials, (cont'd)

- Slide 8
 - Finally Section 6, *Getting Practical*, is the last section and covers how to practically apply everything we have learned about.
 - This section includes two parts—each with a slide deck, and three templates.
 - Part One, *How can our PFAC partner in diagnostic quality and safety activities?*, provides a quick refresh of the "What if?" Template, and emphasizes the relevance of lived experience in diagnostic quality work. It also introduces the Patient Engagement Template, a tool to sketch out exactly how we would be involved in whatever diagnostic quality project we elect to take on.
 - Part Two, *Finding our Project!*, includes a facilitated discussion and brainstorm about the ideas for diagnostic quality projects we want to consider; it then provides tools and guidance for prioritizing and narrowing down our list to a smaller group of project ideas that we can evaluate for strengths and weaknesses. Finally, we'll narrow down to a single project idea and begin to develop a project plan using the tools provided.
 - The templates from this section include the Patient Engagement Template, the Evaluating Impact and Difficulty matrix tool, and an abbreviated Project Plan Template, adapted from a Quality Improvement project tool developed by Johns Hopkins University.
- Slide 9
 - We have looked now at all of the materials provided in the Toolkit, but what is required of us? What is our role as we progress through these sections?
 - Making time to listen and learn about new concepts
 - Brainstorming and sharing ideas
 - Reflecting on our own diagnostic experiences
 - Rolling up our sleeves to identify project opportunities and make plans to reduce diagnostic error.
 - Let's pause again to see if anyone has any questions or comments before we move on?
 - Allow 3-4 minutes for questions or comments before moving on to the next slide.
- Slide 10
 - As we will at the end of each portion of information within a section, let's take a minute to review everything we've just covered and shared.
 - We started with examining all of the materials and activities in the Toolkit. We just learned about the expectations and needs for our involvement. And we began with a clear explanation of the goals of the Toolkit.
 - Is there anything else anyone wants to ask or say before we close?

Section 1. Part Two: Introduction and How to Use this Toolkit - Overview of Sections and Materials, (cont'd)

- Slide 11
 - Thank you so much for your time and participation—this was a great and productive session! The next section will be Section 2, the Introduction to Patient and Family Engagement.



Section 2: Introduction to Patient and Family Engagement

Part One, What is it, how does it work, and why is it so important? and Part Two, The Role of Patient and Family Advisory Councils of Section 2 involve group discussions. You will need to capture the ideas and comments in a way that is visible to everyone. For in-person meetings, this can be a flip-chart, whiteboard, chalkboard, or something similar. For virtual meetings (or in-person), you can add a blank slide to the slide deck you're showing and capture notes and thoughts in real time. To add a blank slide, you'll need to show the slides in "edit" mode rather than "presentation" mode. Reference to "editable" slides in the guidance below refers to the newly added blank slide as previously described.

Section 2, Part 1: Introduction to Patient & Family Engagement - What is it, how does it work, and why is it so important?

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language, please feel free to be conversational and paraphrase as needed.

- Slide 1
 - Our first section of material is about Patient and Family Engagement. There are two decks in this section, and we will start with some background information.
- Slide 2
 - Over the next several slides, we will be talking and learning about "Patient and Family Engagement" or PFE for short. While some of you may be very familiar with this phrase and this concept, for others of you it may be new. This will be an interactive session and you will have plenty of opportunities to ask questions and provide your perspectives as we explore the material.
- Slide 3
 - This will be an open discussion with the group; you should pose each of the questions on the slide and capture remarks from the group on an editable slide, chalkboard/whiteboard/flipchart. Please note: this information will be used for an activity in Slide 9.
 - Maybe by a show of hands or other acknowledgment, how many of you have heard the phrase patient and family engagement?
 - Acknowledge the nods/shakes/other responses and remark accordingly—for example, "it looks like everyone is at least somewhat familiar" or "it looks like there's a bit of variation."
 - And now let's explore—what does that phrase mean to you?
 - You capture what is shared—you don't need to capture everything verbatim, high-level summaries are fine. Let this discussion go on for a few minutes until everyone who wanted to contribute has contributed, and then remark accordingly "lots of great ideas" or "thanks so much for sharing these."



Section 2, Part 1: Introduction to Patient & Family Engagement - What is it, how does it work, and why is it so important?, (cont'd)

- (Slide 3, cont'd) And finally, have any of you been involved in patient and family engagement activities and if so, what were they?
- You capture what is shared in high level summaries. Let this discussion go on for a few minutes until everyone who wanted to contribute has contributed, and then remark accordingly “lots of good examples” or “thanks so much for sharing these.” Note: this information will be used for an activity in Slide 9.
- Slide 4
 - Highlight examples of PFE activities and outcomes.
 - As many of you have shared, there are so many ways that PFE happens! In addition to what was mentioned, I want to highlight the examples listed on the slide—such as shared decision-making between patients and providers, which ensures patients can express their desired goals and needs. Or patients advocating for policy change at the system level—which is so important for making sure policies address the things we as patients care most about. Additionally, patients serving as faculty members and helping to train clinicians is another example—which can help providers see patients as partners in their care, instead of only passive recipients of care.
 - Patients can't be “engaged” in their own care if the discharge instructions they get from the hospital aren't clear and easy to understand. Educational materials for patients are also very important as are easily accessible online medical record portals that give us access to important information about our health. Patients can also be advocates who work to pass laws on all kinds of issues related to their care. Even creating flexible hospital visiting hours has an effect on patients and their families and can be an important way to support engagement.
- Slide 5
 - One common definition of patient and family engagement is provided here on this slide. “Patients, families, their representatives, and health professionals working in active partnership at various levels across the healthcare system – direct care, organization design and governance, and policymaking, to improve health and healthcare.”
 - But as you've seen, there are so many activities and ideas that fall under the umbrella of “patient and family engagement”, and the phrase means different things to different people, and it can cause confusion.
- Slide 6
 - One way to help to avoid that confusion is to divide the many patient engagement activities into two main types. The first type, “Type A” or “personal engagement”, describes patients and families who are actively involved in their own diagnosis and care. The second type, “Type B” or “system level engagement”, is patients and families who are actively involved in efforts at the system or organizational level. We'll look at each type in a little more detail.
- Slide 7
 - Personal engagement (type A) would include activities like being active in your own care—taking notes, asking questions, accessing and using information in your patient



Section 2, Part 1: Introduction to Patient & Family Engagement - What is it, how does it work, and why is it so important?, (cont'd)

(Slide 7, cont'd) portal, feeling like you can have shared decision-making with your provider, and becoming informed and educated about your health and any conditions you may have, but many other things fall under this type A engagement.

- Slide 8
 - System level engagement (Type B) would include things like serving on a PFAC—again, like all of you! This could also mean partnering on a research team at the hospital—so not being involved in research as a “participant” or “subject”, but sitting side by side with researchers and clinicians to design and conduct research. Another example is patients being involved as patient or family faculty at the hospital—helping to teach or evaluate clinicians or students.
 - There is not a type of patient engagement that is better than the other—both are very important and each one feeds into the other. For example, in order for a hospital to develop effective strategies and programs to support patient and family engagement in their own diagnosis and care—Type A or personal—they should partner with PFACs or other patient and family members to develop those strategies—Type B or system level.
 - One of the reasons it is helpful and important to distinguish between the two types of patient engagement, is that MOST people are really referring to Type A engagement when they say “patient and family engagement”. That can create barriers for patients and families who want to engage in Type B engagement activities. Throughout the sections of this Toolkit, we’ll use this Type A and Type B distinction so that we can avoid any confusion about what we’re talking about.
 - Let’s pause here for questions—does this make sense? Any questions about this distinction? There are certainly activities that may fall somewhere in the middle, so this is not a perfect “division”, but it is often very helpful.
 - Pause for questions and comments for 2-3 minutes, and then when conversation has ended or when 2-3 minutes have passed, indicate that you are going to move on
- Slide 9:
 - Now that we have talked through the division between the two types of engagement, we can look back at this list of activities and those that you all shared earlier and start to see which ones are which type.
 - Start with the list you compiled (either on the editable slide or the flip chart or whiteboard in the room) from what the PFAC contributed during slide 3 and ask the group to offer thoughts on whether each activity is A or B, and then do the same thing using the list on slide 9.
 - For the items on the slide, encourage PFAC members to offer answers, but if needed, you can provide the following guidance—and remember that no answers are “wrong”, necessarily, but generally speaking:
 - Shared decision-making is Type A or personal
 - Advocating for policy—like at the federal or state level is Type B or system level

Section 2, Part 1: Introduction to Patient & Family Engagement - What is it, how does it work, and why is it so important?, (cont'd)

(Slide 9, cont'd)

- Patient faculty teaching students is Type B or system level
 - Using patient-friendly hospital discharge language is Type A or personal
 - Educational materials for patients is Type A or personal
 - Easy to use online portals is Type A or personal
 - Pushing to pass laws to improve access to healthcare is Type B or system level
- Slide 10
 - Lead a discussion using an editable slide, chalkboard/whiteboard/flipchart, asking the group to answer the following questions.
 - Thinking first about Type A or personal engagement—so engagement of patients and families in their own diagnosis or care—can any of you share an example of when your engagement in your (or your loved one's) own diagnosis or care was beneficial? Or how a lack of engagement—not having enough information, not having a good partnership with a healthcare provider—caused a poor outcome?
 - Let the discussion go on for 5-6 minutes before moving to the next slide. Capture what is shared (in high level summaries) on either the editable slide you added, or the chalkboard/whiteboard/flipchart. *Note that anything particularly interesting or important may be something you want to circle back to later in the Section or in later Sections, or keep on the radar for a future project. If folks are shy to talk or there are not many volunteers to speak, move to the next slide sooner. When the conversation feels like it is winding down, indicate you're moving to the next slide and thank them for contributing (i.e., "thank you for sharing those examples!").
 - Slide 11:
 - What we know from research and from years of evidence is that patients who are engaged in their own diagnosis and care have better health outcomes.
 - Slide 12:
 - Lead a discussion using an editable slide, chalkboard/whiteboard/flipchart, asking the group to answer the following questions.
 - Thinking now about Type B or system level engagement—so engagement of patients and families in efforts at the system or organizational level to change and improve healthcare—can any of you share an example of how this type of engagement was beneficial? Or how a lack of engagement—not having any patient or family partners to help build solutions—backfired?
 - Let the discussion go on for 5-6 minutes before moving to the next slide. Capture what is shared (in high level summaries) on either the editable slide you added, or the chalkboard/whiteboard/flipchart. *Note that anything particularly interesting or important may be something you want to circle back to later in the Section or in later Sections, or keep on the radar for a future project. If folks are shy to talk or there are not many volunteers to speak, move to the next slide sooner. When the conversation feels like it is winding down, indicate you're moving to the next slide and thank them for contributing (i.e., "thank you for sharing those examples!").



Section 2, Part 1: Introduction to Patient & Family Engagement - What is it, how does it work, and why is it so important?, (cont'd)

- Slide 13
 - Even though this type of patient and family engagement—type B or system level, has not become the norm across all of healthcare, we have made great strides over the past two decades and the evidence of the value of this type of engagement is growing at a rapid pace. We will look next at two examples of how Type B or system-level engagement has made a difference.
- Slide 14
 - Because this whole Toolkit is focused on diagnostic quality, we will look at two examples focused on improving diagnosis.
 - First, in a project about improving the diagnosis of pregnancy-related conditions in the emergency department, the issue of awareness came up—that clinicians may not know or realize that a person recently had a baby, and a person who recently had a baby may not know they should report that information to the folks at the emergency department. Heart and other complications can arise even months after a pregnancy. Patient and parent advocates and clinicians talked about ways to address this problem. The patients suggested having signs in the waiting room or in the emergency room, encouraging them that it would be valuable to share news of a recent pregnancy with the medical team. They also shared that it would be important that the medical teams in the emergency department receive training to know that a recent pregnancy was very important information because of the risks of complications. Having that first-hand experience from patients was key to understanding what would be most helpful and likely to support them in a situation like this.
- Slide 15
 - This second example is really a combination of projects—and an example of what goes wrong when patients and families are not partners in efforts to try to improve diagnostic quality. There have been many projects to address the issue of patients not scheduling or not completing follow-up tests like x-rays or CT scans that were prescribed by their doctors. The projects almost always focus on increasing the number of reminders to patients, assuming the reason patients are not completing these tests is because they aren't remembering to follow up.
 - While some patients may just be “forgetting”, any of us with lived experiences with illness or injury know that there are a host of barriers that have nothing to do with “remembering” to schedule the follow-up test. For example, spending hours on the phone to try to schedule a follow up appointment or test, having to miss work or travel great distances to get to the place that has the test, not having transportation to get to the place that has the test, insurance companies denying authorization for the test—are just some of the many reasons! Wouldn't it be great if patient partners were invited to help design solutions to this problem?
 - Let's pause for a minute and see if there are any questions over what we've covered—or any additional examples of either Type A or personal engagement or Type B or system level engagement that have come to mind for you.



Section 2, Part 1: Introduction to Patient & Family Engagement - What is it, how does it work, and why is it so important?, (cont'd)

- (Slide 15, cont'd) Pause and give the PFAC members a minute or two to ask clarifying questions or offer examples; if they share an example, be sure to capture it in an editable slide or on the flipchart/whiteboard/chalkboard in the room. When it is time to wrap up, indicate you are moving to the next slide and thank them for their contributions
- Slide 16
 - Let's take a minute to review everything we've just covered and shared. We started with looking at the phrase "Patient and Family Engagement" and how it means many different things to different people and covers a whole host of important activities. You all then shared your rich and important experiences with patient and family engagement. Next we learned about the Type A or personal and Type B or system level engagement distinction that we can use to help clarify which type of engagement we're talking about in our work. And finally we ended by discussing why engagement is so very important. Is there anything else anyone wants to ask or say before we close?
 - Pause and give the PFAC members a minute or two to ask clarifying questions. When it is time to wrap up, indicate that this section is concluding.
- Slide 17
 - Thank you so much for your time and participation—this was a great and productive session!
 - The next session in this section of material will focus more specifically on how Patient and Family Advisory Councils do Patient and Family Engagement.

Section 2, Part 2: Introduction to Patient & Family Engagement - The Role of Patient and Family Advisory Councils

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language, please feel free to be conversational and paraphrase as needed.

- Slide 1
 - This is the second part of Section 2, *The Role of Patient and Family Advisory Councils*.
- Slide 2
 - Over the next several pages, we will be talking and learning about how successful PFACs are able to be so effective. Let's start by hearing from you. When you think about what would make this PFAC most effective—or what has made our PFAC effective, what comes to mind?
 - Let the discussion go on for 3-4 minutes before moving to the next slide. Capture what is shared (in high level summaries) on an editable slide, chalkboard/whiteboard/flipchart. *Note that anything particularly interesting or important may be something you want to circle back to later in the Section or in later Sections, or keep on the radar for a future project. If folks are shy to talk or there are not many volunteers to speak, move to the next slide sooner. When the conversation



Section 2, Part 2: Introduction to Patient & Family Engagement - The Role of Patient and Family Advisory Councils (cont'd)

(Slide 2, cont'd) feels like it is winding down, indicate you're moving to the next slide and thank you them for contributing (i.e., "thank you for sharing those ideas!")

- Slide 3
 - The Institute for Patient and Family-Centered Care or IPFCC is an important organization for PFACs; they convene meetings of PFACs, collect and share resources, and study best practices.
 - IPFCC has developed a list of common characteristics among effective PFACs, and many of them are listed here. Let's go through these one by one.
 - Go through (and read) each item and invite the group to react. Prompt with things like "Is this true of our PFAC?", "Does this make sense for our PFAC?", or "If this doesn't already exist, what could we do to take some steps in this direction?"
 - At least 50% of the members are Patient or Family Advisors (PFA)
 - The chair or co-chair is a PFA
 - They have establish guidelines
 - They meet at least 10-12 times per year
 - They have an agenda and keep minutes from the meetings
 - They provide orientation and training to new and ongoing members
 - They establish annual goals
 - They seek a balance of projects initiated or started by PFAC members, and projects initiated or started by others at the hospital
 - They evaluate their effectiveness
- Slide 4
 - So we've talked for a little while about the characteristics that make a PFAC strong and effective, let's shift now to the ways PFACs can have an impact.
 - Invite the group to talk about what they've been working on—including from a historical perspective, using the three questions on the slide. Capture what is shared (in high level summaries) on an editable slide, or chalkboard/whiteboard/flipchart. Give each question 1-3 minutes and when the conversation feels like it is winding down, indicate you're moving to the next slide and thank them for contributing (i.e., "thank you for sharing that input!").
 - Let's think about our own activities—what are we working on?
 - What are we proud of?
 - What would we like to do next?
 - *Note that for the last question anything particularly interesting or important may be something you want to circle back to later in the Section or in later Sections, or keep on the radar for a future project.
- Slide 5
 - Thank you for sharing your ideas and experiences; now let's look at how other PFACs have been able to make a difference.

Section 2, Part 2: Introduction to Patient & Family Engagement - The Role of Patient and Family Advisory Councils (cont'd)

- Slide 6
 - At Brigham and Women's hospital, the PFAC has contributed to a number of initiatives, two of which are featured here. First, they partnered in the creation of a guide for patients and families being admitted to the hospital. Anyone who has been admitted knows it can be overwhelming and scary. This guide helps explain the steps and let's folks know what options are available to them if they have needs or concerns while they're in the hospital.
 - Second, the PFAC was very involved in the redesign of the emergency department, making sure the space is as accessible and welcoming as possible, and is responsive to all of the needs of patients and families. Emergency departments can be so scary and no one knows better than patients and families who have spent time in them, how they can be enhanced to be less unsettling.
- Slide 7
 - At Johns Hopkins, a PFAC member reviewed and provided feedback on a survey used to evaluate the experience of Johns Hopkins research participants. PFAC members can be involved in any aspect of the hospital or health system's work, including research and quality improvement.
 - For more examples, please consult the "Additional Resources" on the Toolkit website, as well as the IPFCC website which collects PFAC "exemplars".
- Slide 8
 - You might remember from the last session our discussion of Type A or personal and Type B or system level engagement. This would be a good time to narrow in on WHY PFACs are such critical partners. You have all come to this "room" because you have lived experiences with the medical system—what we call Type A engagement. And now you can use that lived experience to inform efforts to improve care and safety for everyone served at the hospital—what we call Type B engagement.
- Slide 9
 - As we work through this Toolkit, we'll be learning about the ways PFACs can support efforts to keep patients and families safe during the diagnostic process. For PFACs to be most successful in this type of work there are a few specific qualities that are necessary. The PFAC needs to have a strong connection and a solid relationship with the hospital leadership. The PFAC should have a strong partnership with the community of patients and families served by the hospital—including ways to collect feedback and be responsive to community needs. Lastly, the PFAC should be advocating for the involvement of patient and family partners in all activities.
 - Let's pause for a minute and talk about where our PFAC has strengths and where we might need to build some capacity—or develop relationships.
 - Using the questions below, invite the group to a discussion for 3-4 minutes on each one before moving on. Capture what is shared (in high level summaries) on an editable slide, or a chalkboard/whiteboard/flipchart. *Note that anything particularly interesting or

Section 2, Part 2: Introduction to Patient & Family Engagement - The Role of Patient and Family Advisory Councils (cont'd)

(Slide 9, cont'd) important may be something you want to circle back to later in the Section or in later Sections, or keep on the radar for a future project. When the conversation feels like it is winding down, indicate you're moving to the next slide and thank you them for contributing (i.e., "thank you for sharing those ideas!").

- Is there anything we need to work on in terms of our relationships with hospital leadership? What can we do?
 - What has our experience been with connecting to our broader community of patients served by this hospital? What should we explore or consider?
 - What have we been doing in terms of advocating for the inclusion of patient and family advocates in all of the safety and quality work of this hospital? What do we need to be doing?
- Slide 10
 - Let's take a minute to review everything we've just covered and shared. We started with talking about the qualities of effective PFACs. Next we discussed and learned about the types of activities PFACs undertake, including this PFAC's major wins—and hopes for future activities.
 - We looked at a couple of key attributes most PFACs have and what this PFAC has at its disposal, and why the work of PFACs is so important. Is there anything else anyone wants to ask or say before we close?
 - Capture what is shared (in high level summaries) on an editable slide, or chalkboard/whiteboard/flipchart.
 - Slide 11
 - Thank you so much for your time and participation—this was a great and productive session!
 - The next section in the Toolkit is about diagnosis and diagnostic safety.



Section 3: Understanding the Diagnostic Process and Diagnostic Safety

The first part of Section 3 involves an interactive exercise with group discussion, but for this exercise there will not be a need to capture the input and feedback. For the diagnostic process map exercise in the first deck, you can either open up the interactive process map directly from the Society to Improve Diagnosis website (<https://www.improvediagnosis.org/processes/the-diagnostic-process/>), or use the step-by-step version of the map in the deck. The Key Drivers diagram will need to be shown using the step-by-step version in the deck. The second deck will also include many interactive discussions, and both involve group discussions, but again there will not be a need to capture feedback and input in real time. You will need to project the slides in your meeting room or, if you meet virtually, broadcast the slides from the Zoom or other online platform.

Section 3, Part 1: Understanding the Diagnostic Process and Diagnostic Safety - Diagnosis and the Diagnostic Process

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language, please feel free to be conversational and paraphrase as needed.

- Slide 1:
 - This is the first part of Section 3, *Understanding the Diagnostic Process and Diagnostic Safety*.
- Slide 2:
 - Start with a group discussion of the term “diagnosis” by asking the following question.
 - Even though it is a single word, the word diagnosis actually represents a whole process. Thinking about your own medical care, what types of experiences have you had with getting a diagnosis?
 - Pause for input, if none or slow, start to offer prompts (below) to invite conversation
 - For example, the process of diagnosis could include testing the blood or urine or other fluids, or taking images with x-rays or CT scans, or even having exploratory surgery. Has anyone had experience with one or more of those things?
- Slide 3:
 - This image is called the Diagnostic Process Map, created by the National Academies of Medicine. This map explains in detail each step of the process of getting a diagnosis. The Society to Improve Diagnosis in Medicine, and the Academies developed an interactive version of the map and that’s what we’re going to walk through next.
 - You will need to open up the interactive diagnostic process map from the SIDM website, or use the deck with provides a step-by-step version of the map with your discussions prompts for each.

Section 3, Part 1: Understanding the Diagnostic Process and Diagnostic Safety - Diagnosis and the Diagnostic Process, (cont'd)

- Slide 4
 - As you can see there are many parts of the diagnostic process, but we will review each piece one at a time. Please note that each step is color coded to align with the map.
 - At the beginning of the map, we see that a patient experiences a health problem. The patient may resolve the situation on their own, or consult with others to find an explanation of the issue.
- Slide 5
 - Next, the patient, if they choose to do something about their issue, will have their first interaction with the health care system. There are many factors that go into the decision about whether or not to seek care. Concerns about cost or access to care can be barrier—for example, not having a “regular” doctor or worry about not being able to pay for care. Trust is also a major issue—patients that have had negative experiences with healthcare previously may be nervous to seek care. Choosing to seek care begins the “formal” diagnostic process.
 - Let’s pause here and see if anyone has questions or comments on what we’ve just reviewed.
 - This can be a short pause, just to be sure no one is confused.
- Slide 6
 - Now that the patient is in the health care system, the next three pieces function together to start identifying a diagnosis.
 - There are two main steps here—the patient reporting their own medical history and sharing what’s going on, and the clinician performing an exam on the patient. There may be other tests needed at this time such as x-rays or blood tests, depending on what the issue is.
- Slide 7
 - This step in the diagram explains how the clinician (or group of clinicians) start to pull the information together. They do this by drawing on their medical knowledge and interpreting gathered information to identify patterns that suggest specific diseases or disease types.
 - With approximately 200 known symptoms but over 10,000 possible diseases, there are often many possible diagnoses!
 - Clinicians should involve patients in the diagnostic process, discussing how their symptoms do or do not match different possible diagnoses, and asking the patient for their perspectives and input.

Section 3, Part 1: Understanding the Diagnostic Process and Diagnostic Safety - Diagnosis and the Diagnostic Process, (cont'd)

- Slide 8
 - With as much gathered information as possible, the clinician now starts identifying the options--creating a prioritized list of potential diagnoses (called differential diagnoses).
 - The most likely choice from the list is often designated as the working diagnosis, indicating it is a strong possibility but is not yet confirmed, and indicating that other possibilities are not yet ruled out. The working diagnosis should be shared with the patient so they are aware of what is suspected.
 - As more information is gathered, the clinician continues to work through the list.
 - Let's pause here for a moment—does anyone have any questions or is this making sense so far?
 - Allow for a few minutes of discussion and clarification if needed then move on.
- Slide 9
 - On the next few slides we will do a deeper dive into each of these elements of the appointment or assessment: Clinical History & Patient Interview, Physical Exam, Referral & Consultation, and Diagnostic Testing.
- Slide 10
 - We briefly touched on the patient's history earlier, but now we can see in more detail the important information that comes about from this conversation. A patient's clinical history includes their current concern—the “thing” that has prompted them to seek care, past medical and family history, any aspects of their work or social life that might be relevant, any current medications or clinical regimens, and anything else that could be helpful—such as recent travel.
 - Collecting a full and accurate history requires active listening and skilled interview techniques on the part of the clinician, and as much openness and accurate reporting as possible on the part of the patient.
- Slide 11
 - The physical exam is another important information gathering activity—and as you see here, often includes examination of the whole body rather than only the part or parts that appear to be affected by the person's current concern.
- Slide 12
 - The next component to consider is diagnostic testing—which allows for information beyond what the naked eye can see. This can involve testing the blood, urine, or other body fluids, taking tissue or other samples to analyze for infection or presence of disease, taking images of the affected body part, or even performing exploratory surgery or other procedures if needed.



Section 3, Part 1: Understanding the Diagnostic Process and Diagnostic Safety - Diagnosis and the Diagnostic Process, (cont'd)

- Slide 13
 - Finally, the important step of referral or consultation, if needed. Clinicians may consult with their peers, asking them to weigh in on the case and aide in confirming or rejecting the working diagnoses. When a health problem exceeds a clinician's expertise, they should refer the patient to a specialist. Sometimes patients themselves feel a second opinion from another clinician is needed, either because they are not entirely satisfied with the first explanation, or just because getting a second opinion can be a good idea for complicated issues.
 - Let's pause here and reflect on what we've just learned. Have you ever thought of diagnosis as a process before? Have you all experienced each of these steps? If not, which pieces were missing? Is the term "working diagnosis" familiar to you?
 - Allow the group a few minutes of discussion before moving on.
- Slide 14
 - A critical element of timely and accurate diagnosis is communication. The patient's health problem should be explained fully in understandable terms, but also in combination with the appropriate medical terminology so the patient knows exactly what the issue is—for example, telling the patient they are experiencing a sudden heart attack (which is in lay language), but also explaining that in medical terms this is called an acute myocardial infarction. Clinicians should confirm the patient's understanding of the diagnosis, address questions, and ensure they understand the necessary next steps.
 - This may be a new way of thinking about diagnosis—but communication is considered an important part of diagnosis. What have your experiences been with having a diagnosis communicated—or not?
 - Allow discussion for a few minutes before moving on to the next slide.
- Slide 15
 - Once the diagnosis has been communicated, it may be time to begin treatment. Sometimes a treatment is started as a test—to see if it will work. In those cases, the treatment is used as another tool to find the right diagnosis; if the treatment does not work for the suspected diagnosis, it may mean it was the wrong diagnosis. Other times the treatment plan is more firm because the diagnosis is more definite. And still other times it may not be possible to start treatment because the diagnosis is still too unclear.
- Slide 16
 - And perhaps most importantly are the outcomes from the diagnostic process. Did the issue resolve? Is the patient doing well? Was the diagnosis caught quickly enough to avoid unnecessary harm?
 - Here again, treatment and outcomes may not be things we have linked with diagnosis before, but as you can see, they are an important part of this cycle. If the treatment doesn't work after a certain amount of time, it may be necessary to back up a few steps and restart the process as you can see in the graphic.



Section 3, Part 1: Understanding the Diagnostic Process and Diagnostic Safety - Diagnosis and the Diagnostic Process, (cont'd)

- (Slide 16, cont'd) Has anyone had experience with revisiting a diagnosis before? Needing to go through the cycle more than one time in order to land on the right diagnosis?
- Allow for a show of hands or nods, and if someone offers an example, allow 2-3 minutes to discuss, otherwise, move on to the next slide.
- Slide 17
 - Now that we have discussed and learned the diagnostic process map, we are going to look at some of the main factors that influence diagnosis.
 - What we see here is a version of what is called the “Key Drivers Diagram”, which was created by a team of people studying diagnosis. They identified a few key “drivers” that can help make diagnosis happen more quickly and correctly.
 - First is teamwork. Diagnosis is a “team sport” because each person on the team brings a different perspective. For example, a nurse might be seeing a decline in a patient that the physician isn’t seeing because she hasn’t spent as much time in the room. It is important that every team member is heard and has an opportunity to weigh in on what’s happening.
 - As you think about your own care, have you ever had experiences in which different members of the care team responded differently or maybe you had a connection with one team member and not others?
 - Pause and allow 2-3 minutes for input or discussion.
- Slide 18
 - Next is the presence of reliable diagnostic processes; this is really about the “technical” parts of making a diagnosis—like making sure blood tests are done correctly or making sure the right information is entered about the right patient in an electronic medical record. So you can imagine why that is an important piece. Does anyone have any questions or comments about this piece of diagnosis?
 - Pause and allow 2-3 minutes for questions or discussion.
- Slide 19
 - Now we come to the engagement of patient and family members in the diagnostic process—and this one speaks for itself! As we all know, it is so important that patients and families are engaged in their own care and their diagnostic processes—so this “driver” is about making sure patients and families are looked to as partners—that they are given the right information, that they can contribute their own thoughts and ideas, etc. What are your experiences with being included—or not being included—in your own care? Or in the process of getting something diagnosed?
 - Pause and allow 2-3 minutes for discussion.



Section 3, Part 1: Understanding the Diagnostic Process and Diagnostic Safety - Diagnosis and the Diagnostic Process, (cont'd)

- Slide 20
 - Next is optimized cognitive performance, which is basically a fancy way to say “how clinicians think”—how they pull together all the pieces of information from us as patients, from tests, from our history, and try to make a determination of what the likely issue is. You’ll remember from the diagnostic process map, this is the circle in the middle—gathering information, integrating and interpreting that information, and then determining a “working diagnosis”. Sometimes it takes time to know if the diagnosis was right—if treatment is used, and it doesn’t seem to work, there might be something we need to go back to at the beginning of that cycle—was something missed? Could it be something else? And try a second time.
 - These thought processes can be helped through training, and practice, and increasingly, technology. Does anyone have any questions or comments to share on this topic?
 - Pause and allow for 2-3 minutes for discussion.
- Slide 21
 - And finally, there is a need for robust learning systems—so, opportunities to stop and study and learn—what’s going well at this hospital? What’s not? When there is a mistake—a diagnostic error—do we learn from it, and put processes or systems in place to make sure it doesn’t happen again? This can include things like reporting systems, or evaluations to see how well the hospital is doing.
 - In thinking about your own care, or about our hospital, are you aware of any systems like this in place that try to study what’s going on and understand if the diagnostic process is working as well as it can?
 - Pause and allow for 2-3 minutes of discussion.
- Slide 22
 - We have discussed a lot today, so let’s take a minute to review everything we’ve covered and shared.
 - We began with reviewing and exploring the National Academies/SIDM interactive diagnostic process map which walked through each step of the diagnostic process, including the cyclical nature of the process—that sometimes it is necessary to go around the loop more than once to identify what the issue really is.
 - Here, integrate any comments or questions from the group that would be valuable to repeat such as examples folks shared during the diagnostic process map exercise.
 - We then reviewed some of the best practices in the field of diagnosis—these were called the “key drivers” that can support accurate and timely diagnosis. Effective teamwork—so, all members of the team have a say and work together, reliable diagnostic processes—the technical pieces like blood tests and electronic medical records, patient and family engagement— patients and families are PART of that diagnostic team,



Section 3, Part 1: Understanding the Diagnostic Process and Diagnostic Safety - Diagnosis and the Diagnostic Process, (cont'd)

(Slide 22, cont'd) optimal cognitive performance—meaning, clinicians are best able to process and integrate information to make a diagnosis, and finally, robust learning systems—which means there are things in place to make sure we learn from what goes well and doesn't go well.

- Is there anything else anyone wants to ask or say before we close?
- Pause and allow for 2-3 minutes of discussion.
- Slide 23
 - Thank you so much for your time and participation—this was a great and productive discussion! The next section in the Toolkit is about when things break down in the diagnostic process—what we call diagnostic error.

Section 3, Part 2: Understanding the Diagnostic Process and Diagnostic Safety - Introduction to Diagnostic Error

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language, please feel free to be conversational and paraphrase as needed.

- Slide 1:
 - This part of section 3 is an *Introduction to Diagnostic Error*.
- Slide 2:
 - In the last section, we learned all about the process of diagnosis and what can help diagnosis to be accurate and timely; now we're going to shift gears and talk about what happens when that process goes wrong.
 - Let's start with the basic definition of a diagnostic error. This definition came from the Leapfrog and Society to Improve Diagnosis in Medicine's Recognizing Diagnostic Excellence Project which explains that diagnostic error is 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 and/or
 - Diagnosis is not communicated to the patient: Accurate diagnosis was available but was not effectively communicated to the patient or family.
 - Let's pause for a minute...first, any questions about this definition?
 - Allow 2-3 minutes for questions or discussion.
 - Does anyone have examples or experiences with diagnostic error they want to share—these could be your own or those of your loved ones? Please avoid using the names of any providers or hospitals/institutions where the errors occurred.
 - Allow 4-5 minutes for discussion.

Section 3, Part 2: Understanding the Diagnostic Process and Diagnostic Safety - Introduction to Diagnostic Error, (cont'd)

- Slide 3
 - One way to learn about diagnostic error is to start by thinking about what makes a diagnosis “good”, and then flip those qualities. A simple way to think about a “good” diagnosis is that it was accurate (it needs to be the right diagnosis), timely (it should be identified as soon as possible), and communicated in a way the patient and family can understand. Even if a diagnosis is accurate and timely, if it is not communicated to the patient or family in a way they can understand and take action, the patient can still be harmed.

- Slide 4
 - Let’s spend a little more time on each of these pieces by learning from some of the patient stories in the Society to Improve Diagnosis in Medicine’s Patient StoryBank. This is a resource for patients or family members to share their diagnostic error story so that others can learn from their experiences and use them as teaching tools.

 - Julia Berg’s story is an example of how important the accuracy of the diagnosis is. She 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 Dan and his wife 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 coded and died—from complications of an undiagnosed case of mononucleosis—or, mono.

 - Julia’s parents, Dan Berg and Welcome Jerde 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. Dan is also very active as a volunteer with SIDM.

- Slide 5
 - Susie Becken lost her son Chad to a delay in diagnosis of his colorectal cancer.

 - Chad sought care for an array of worrisome symptoms including low back pain, fatigue, and weight loss. He was seen by a number of 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, Susie became very active in the patient safety movement, serving on her local Patient and Family Advisory Council, and partnering with SIDM on a number of diagnostic quality projects.

Section 3, Part 2: Understanding the Diagnostic Process and Diagnostic Safety - Introduction to Diagnostic Error, (cont'd)

- Slide 6
 - And lastly, Steven Coffee II's rare metabolic disorder was not explained to his family.
 - 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 he 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, the family was not made aware what the condition was or how to manage it. Ultimately, complications of the condition caused the baby to develop fulminant liver failure and require a liver transplant. Now a healthy young man, these severe complications could have been avoided with clearer and more accessible information about the diagnosis.
 - After his son's experience, Col. Coffee became a very vocal patient advocate, serving as a member of his nearby PFAC, partnering with SIDM on a number of projects, and co-founding with several other advocates Patients for Patient Safety, US, an affiliation of the World Health Organization.
 - Does anyone have any questions or comments about these stories?
 - Allow 2-3 minutes for questions or discussion.
- Slide 7
 - This slide provides some of the most recent facts and figures on the diagnostic errors in the United States. As you can see, 1 in 20 patients will experience a diagnostic error in the outpatient setting each year, and among all of the types of medical errors, patients and families report diagnostic errors more than other types of errors.
 - Across all types of care—including care provided in the hospital—as many as 795,000 people are made permanently disabled or die due to diagnostic errors each year, and diagnostic errors are estimated to cost over \$100 Billion annually.
- Slide 8
 - As we learned in the last section, there are a number of things that hospitals and clinicians do to support accurate and timely diagnosis; this is the diagram we reviewed that outlines five “key drivers” for diagnostic quality and safety. As you think about the examples we've worked through, which of these drivers do you think may have broken down?
 - Allow for a few minutes of discussion before moving to the text below and then on to the next slide.

Section 3, Part 2: Understanding the Diagnostic Process and Diagnostic Safety - Introduction to Diagnostic Error, (cont'd)

- (Slide 8, cont'd) Even though diagnostic errors happen, it is also important to recognize that correct diagnoses are made every day! Working in diagnostic quality happens in both directions—efforts to prevent harm from errors, and efforts to promote and ensure quality.
- Slide 9
 - There are also resources to help patients and families through the diagnostic process, helping them prepare for appointments, track symptoms, and try to best navigate what may be a complicated process.
 - One of these resources was created by patients on the Patient Engagement Committee of the Society to Improve Diagnosis in Medicine, called the Patient's Toolkit for Diagnosis—these patients had experiences with diagnostic errors themselves. This Toolkit is accessible on SIDM's website and we'll go through it together over the next few pages.
 - This first page, as you can see, is the instructions for how to use the Toolkit. It explains that the Toolkit should be filled out prior to a visit, to help the patient best partner in their care, provide the most relevant and important information to the clinical team, and keep track of what happens during and after the visit.
- Slide 10
 - This first page is focused on preparing for medical appointments; as you can see, information is broken into several sections, and the idea is to spend time gathering and entering the information before your clinic visit.
 - One of the most important suggestions in the Toolkit is the list of questions at the bottom of this page; these are ideas for questions patients/families may want to ask in a visit—and again, this Toolkit was developed by people who have experienced problems with getting the right diagnosis, so these questions were informed by those experiences.
 - Maybe most important—what is my diagnosis?
 - What makes the clinical team think that is the most likely diagnosis?
 - Is there more information I can access about the diagnosis?
 - Are there more tests or any treatment I need—and can you explain those to me?
 - Are there any risks to these tests or treatment? What would happen if I did not follow up with these tests or treatments? Would that be harmful to me?
 - When do I need to follow up with you and how do I do that?
 - What should I do if my symptoms change or get worse?
 - Any questions or comments before we move to the next page?
 - Allow 2-3 minutes for questions or discussion.



Section 3, Part 2: Understanding the Diagnostic Process and Diagnostic Safety - Introduction to Diagnostic Error, (cont'd)

- Slide 11
 - Next we have a page that helps someone think through their symptoms and make careful notes about what has been going on with their health. It has a diagram of the body to allow you to note the location of symptoms; it asks questions about pain, type of pain, and severity of pain, and any ongoing treatments for symptoms.
 - Any questions or comments before we move to the next page?
 - Allow 2-3 minutes for questions or discussion.
- Slide 12
 - As you can see, this page focuses on medication; this may seem strange at first, but when a person and their medical team is trying to get to the bottom of a medical issue, having a complete picture of all the possible issues is very helpful. Perhaps the symptoms a person is experiencing are related to a medication they are taking. Or a medication they have stopped taking.
 - Any questions or comments before we move on?
 - Allow 2-3 minutes for questions or discussion.
- Slide 13
 - And lastly, this page is focused on what happens next. This is a place to capture all of the information that was discussed or provided during an appointment, including any instructions for tests or medications. As you've seen now in a few of these sections, diagnosis truly is a process, and so it is important that any needed follow-up happens, including additional appointments, tests or consultations with other clinicians.
 - This page covers not only what needs to happen in terms of clinical follow-ups like testing or appointments, but any changes that need to happen at home. Are you supposed to monitor your symptoms? Change any behaviors—like increase or decrease activity? Change any medications?
 - This is just one such tool, but others exist as well, and those can be found in the supplemental materials available at the end of the Toolkit.
- Slide 14
 - Let's take a minute to review everything we've just covered and shared.
 - We began by discussing the definition of diagnostic error and hearing stories of families affected from missed and delayed diagnosis. We then learned the most recent data about the frequency and prevalence of diagnostic errors, and reviewed the five Key Drivers to support diagnostic quality. Lastly, we reviewed a tool for diagnostic quality that is focused on patients and families—the SIDM Patient's Toolkit for Diagnosis.



Section 3, Part 2: Understanding the Diagnostic Process and Diagnostic Safety - Introduction to Diagnostic Error, (cont'd)

- Slide 15
 - Thank you so much for your time and participation—this was a great and productive discussion!
 - In the next sections of the Toolkit, we will be moving from the big picture of diagnostic quality and safety, to a more specific look at diagnosis at the individual level, and how we can learn from both successful and unsuccessful diagnostic experiences.



Section 4: Diagnosis and You

Part One of Section 4, *Learning from Diagnostic Experiences*, involves an interactive exercise with group discussion, but for this exercise there will not be a need to capture the input and feedback of the group—each person will work on their own exercise. If you are meeting in person, you may want to print of f copies of the “What if?” Template for the PFAC members, and provide paper and pens for people to use. If your meeting is virtual, you should advise everyone to have paper and pen near them or email a copy of the template for them to print out in advance of the class. When you walk the group through the “What if?” Template, you’ll be given an example to share to help explain the exercise to everyone, step by step. The second part of this section is an MP4 file and is meant to be shown like a video. When you get to slide 4 of Part One, you’ll will be prompted to play the instructional video for the group. If meeting in-person, play the video in the room using whatever technology you use to show slides and other materials; if meeting virtually, you should be able to launch and play the video directly through Zoom or whatever your meeting platform is. When the video concludes, you will return to Part One, and work through the “What if?” Template.

Section 4. Part One: Diagnosis and You - Learning from Diagnostic Experiences

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language, please feel free to be conversational and paraphrase as needed.

- Slide 1
 - In this section, we are going to zoom in a bit to the individual level and think more about how we all have experienced diagnosis and the diagnostic process.
- Slide 2
 - So far in this Toolkit, we’ve talked about patient and family engagement—Type A, engagement of patients and families in their own diagnosis and care and Type B, engagement of patients and families as partners and advisors in system or organizational level efforts—like PFACs.
 - We’ve learned about the diagnostic process, diagnostic errors, and some of the practices that patients, clinicians, and hospitals can use to try to maintain diagnostic quality.
 - In this section, we’ll start tying it all together and bringing it back to us, as individuals and as patients and consumers of healthcare.
- Slide 3
 - You’ll remember from previous sections, we reviewed the National Academies diagnostic process map and talked about each of the steps in the diagnostic process.
 - We’ve also done some brainstorming and had discussions about some of your experiences with healthcare, including your experiences going through the diagnostic process.

Section 4. Part One: Diagnosis and You - Learning from Diagnostic Experiences, (cont'd)

- Slide 4
 - For this section we're going to spend some time using an important tool called the What If? template. The tool was designed to help patients, families, PFACs, hospitals, clinicians, and others learn from and share their diagnostic experiences—both good and bad.
 - Some of you may have joined this PFAC because of a diagnostic experience you or a loved one had. That experience will be helpful when learning about and using this tool. For others of you, using the tool might require a little bit of creativity or practice, but it will almost certainly be valuable. Before we dive into the tool we're going to watch a short video that describes how the tool is meant to work, and how different patients or family members have used the tool to describe their diagnosis stories, and identify opportunities for learning about and improving the diagnostic process.
 - The video is hyperlinked at the bottom of slide 4. Click on the hyperlink and make sure the volume is turned up and the video plays correctly. Facilitation is not required during the video—it has both audio and visual effects and is meant to function on its own. When the video concludes, exit out of that screen and return to the Part 1 of Section 4, and advance to slide 5.
- Slide 5
 - Any questions or comments about the instructional video? Now that the idea and the purpose for the What If? template have been explained, we are going to try it out ourselves
 - Pass out hard copy versions of the template for people to use for the exercise; if your meeting is virtual, remind everyone that the template was emailed to them in advance and that they should use their printed or f hard copies or use scratch paper to jot down their thoughts and the responses to the template questions.
- Slide 6
 - Before getting started let's briefly think about what story or experience we'll each use as we fill out the template—focusing on the process of getting a diagnosis. This could be your experience, or someone you know. It could be a good experience or a bad one, it could be something that happened in a hospital, or something that happened outside the hospital in a clinic or physician office. It could be something that happened in just a few days, or something that happened over several month. Everyone is different and our experiences are too. You may not have all of the details about what happened, but that's okay. I'll pause and let you all think for a minute—and feel free to ask questions or share your ideas if you need any help or suggestions.
 - Keep in mind that we won't use last names or any identifying information about the patient, the clinicians or hospital involved, or anything else that must or should be kept private. If you'd prefer not to use the first name of your loved one, you can make up a name to use.



Section 4. Part One: Diagnosis and You - Learning from Diagnostic Experiences, (cont'd)

- (Slide 6, cont'd) Give everyone 60-90 seconds time (adjust as needed) to think about what story or experience they may want to share, be on the lookout for raised hands for folks who need or want clarification about what they should be doing.
- Okay. Does everyone have a story in mind?
- Scan the room to make sure most folks have a story in mind (nodding heads). If someone needs extra time or assistance, give them more time.
- As we work through each section of the template, I will share pieces of an example that comes from one of the creators of this Toolkit, about a problem getting an infection diagnosed after a surgical procedure. Please keep in mind, this is just an example to help explain how to use the template. There is no correct or perfect answer to these questions; everyone's responses will be correct and valuable!
- Slide 7
 - The template starts with some general information and background. The very first question just helps set the stage for who the patient is—whether it is you or your loved one. These should just be very simple answers such as those we saw in the video. They can be details like age, gender, race, or ethnicity, and anything else that seems important to share such as occupation, location, or other key characteristics.
 - The next question is meant to provide some basic information leading up to the experience...what's the background? Had anything been going on or was this problem or symptom brand new? As we saw in the video, everyone's experiences are different from one another, and that means some elements of the template will be a perfect fit and others won't. In some cases you may have to just do your best to interpret what the template is asking of you. Let's take a few minutes to add a few notes to this section.
 - Give 4-5 minutes to allow people to draft their responses in their own templates. After some time has passed, ask if folks are done. If they need more time adjust accordingly. Move to next slide when ready.
- Slide 8
 - So for the example provided in the Toolkit, we see that it was a woman named Nancy, she was 35 and was a nurse. She lived in a rural area and was pretty far away from the nearest hospital.
 - For the background, Nancy had carpal tunnel surgery on her left wrist. The surgery was done outpatient on a Monday, but by Wednesday she was having some unusual and severe pain and had reported it to the surgeon. She had an appointment with him on Thursday, and he said the wound looked fine, so she believed the pain was just normal post-surgery pain. By Saturday morning she was in such pain she decided to go to the Emergency Department at the hospital about an hour away.
 - Is the exercise making sense so far? Does anyone have questions, or do you feel ready to try your own example?



Section 4. Part One: Diagnosis and You - Learning from Diagnostic Experiences, (cont'd)

- Respond to questions or provide additional explanation as needed and when the group seems ready, move to the next slide. Some group members may see the example and want to make some slight changes to their template responses, which is totally fine. If they ask to see the prior slide to be reminded what the questions were, you can skip back to that slide until they're ready to move on and then move on to slide 9.
- Slide 9
 - Our next question gets right into the main points of your story by focusing on the “thing” that ultimately brought the patient to the hospital or clinic. This moment or event is often called the “presentation”—when the patient “presented” with symptoms to whatever the care setting was.
 - We have another question about the “course of care”. This question is a good example of how different people will have very different responses to the template questions because our experiences are so different from one another. Some people’s stories all happened in one hospitalization; other’s happened over the course of many days or weeks with many visits to different hospitals. There are no wrong answers, this is all just a way to capture the main points about what happened and identify the learning opportunities from them.
 - Give 4-5 minutes to allow people to draft their responses
- Slide 10
 - In the example provided in the Toolkit, Nancy arrived to the Emergency Department and explained that she was in extreme pain in the wrist where the surgery had happened. The team taking care of Nancy took a sample of some of the pus on the wound to run tests on it. They also took her temperature and ran several blood tests to see if there were any signs of infection or inflammation in her blood.
 - In terms of the course of care—which in her case was in the hospital—they shared with her that the wound was clearly infected, and that they were running tests to understand how serious the infection was and to identify the type of infection. They started her on a “broad-spectrum” antibiotic and IV fluids while they waited for test results to come back. She ultimately required several weeks in the hospital to receive treatment, fluids, and to monitor for signs of sepsis (the body’s significant and sometimes life-threatening reaction to infection). After she was discharged from the hospital, she required several weeks of physical therapy to regain function in her wrist and hand—beyond what the regular carpal tunnel surgery would have required.
 - Any questions or clarifications here, or are we ready to move forward?
 - Respond to questions or provide additional explanation as needed and when the group seems ready, move to the next slide. Some group members may see the example and want to make some slight changes to their template responses, which is totally fine. If they ask to see the prior slide to be reminded what the questions were, you can skip back to that slide until they're ready to move on and then move on to slide 11.



Section 4. Part One: Diagnosis and You - Learning from Diagnostic Experiences, (cont'd)

- Slide 11
 - This next question is the crux of the story—what was the ultimate diagnosis and how did it come about? At this point in the template, it may feel like the questions are more oriented to a bad or negative diagnostic experience—which is understandable because this was developed in a project about diagnostic errors. However, you can complete these segments even if the story you’re describing is a positive one and I can help you if you run into any challenges.
 - And finally, we start to get into the discussion portion which is where we can really tease out some of the learnings or opportunities. Here again, please don’t provide last names of people or names of specific hospitals or clinics, or other information that would be too private, but general concepts and memories from the experience can be helpful to list out.
- Slide 12
 - In the example provided in the Toolkit, Nancy ultimately got the diagnosis of a MRSA (Methicillin-resistant Staphylococcus aureus) infection in the wound from her carpal tunnel surgery.
 - By the time she came to the Emergency Department, the infection had spread into her bone. Nancy had communicated the “unusual” and severe pain she was experiencing to her surgeon, but he did not see objective signs of infection when he examined the wound, so he diagnosed it as normal post-surgery pain. That allowed the infection to continue to worsen and spread until she decided to seek care in the Emergency Department later that week.
 - Any questions or comments or are we ready to move on to the final step?
 - Respond to questions or provide additional explanation as needed and when the group seems ready, move to the next slide. Some group members may see the example and want to make some slight changes to their template responses, which is totally fine. If they ask to see the prior slide to be reminded what the questions were, you can skip back to that slide until they’re ready to move on and then move on to slide 13.
- Slide 13
 - Now we are at our final question, which is probably the most important one—figuring out what could have been different—the “What if? question, and what can be learned. If it was a negative experience, what would have prevented it? Or what could improve such a thing in the future? If it was a positive experience, what could be repeated or expanded so that more patients could benefit from it? It is okay if you don’t have fully formed ideas here for how to improve the “thing” that went wrong...even just framing it as a question is enough for now. I’ll give you all a few minutes to identify these “What ifs” and any ideas for making improvements—or building on positive things that happened.
 - Give 3-4 minutes to allow people to draft their responses.



Section 4. Part One: Diagnosis and You - Learning from Diagnostic Experiences, (cont'd)

- Slide 14
 - In the example provided in the Toolkit, Nancy wanted to know, What If? the surgeon had believed my reports of unusual and severe pain and suspected an infection even though there weren't visible signs of an infection? She does not have a specific idea for *how* to make that happen—but her idea for what to take away and learn from this experience is that we need better training or better tools to help clinicians better assess patient reports of pain, and to catch infections even if there are not visible signs.
 - Any questions or comments before we move forward?
 - Respond to questions or provide additional explanation as needed and when the group seems ready, move to the next slide. Some group members may see the example and want to make some slight changes to their template responses, which is totally fine. If they ask to see the prior slide to be reminded what the questions were, you can skip back to that slide until they're ready to move on and then move on to slide 15.
- Slide 15
 - Now that we've walked through the template, let's hear some of the What Ifs? or some of the ideas for learning or improvement that were generated during this exercise. You heard and saw the example of Nancy. What experiences did others of you write about?
 - Ask for volunteers and allow 1 or 2 PFAC members to share, or more if time permits. If no one wants to share, you can move on to the next slide
- Slide 16
 - Let's take a minute to review everything we've just covered and shared.
 - In this section, we brought things back to the individual level and used one of the Toolkit templates called the "What If? template" to work through an example of a diagnostic experience, either negative or positive. This is just one example of how PFAC members can bring their lived experience to the work of the PFAC to suggest ideas for projects, or bring things to the attention of others.
- Slide 17
 - Thank you so much for your time and participation—this was a great and productive discussion!
 - In the next section, we'll start to get practical and look at what types of diagnostic quality and safety work this PFAC may want to try to tackle at our hospital.



Section 5: What could we do about diagnostic quality in our hospital?

Section 5 only has one part—a single deck, and it is focused on discussing and identifying opportunities to improve diagnostic safety at your hospital. A key aspect of this section is the need for a strong relationship between the PFAC, hospital leadership, and the people from the hospital who are focused on safety and risk.

If you, or the PFAC in general, already has a relationship with hospital leadership and/or the people who focus on safety and risk, you can note that as you work through the deck, and you may be able to skip over some of the slides that deal with establishing that relationship. You will need to find time for relevant people from hospital leadership and/or the people who focus on safety and risk to meet with the PFAC. You should meet with those individuals ideally before moving to Section 6, but if that is not possible, the meeting can happen after you go through Section 6.

If you, or the PFAC in general, does not already have a relationship with hospital leadership or the folks who focus on safety and risk, Section 5 includes guidance for reaching out and forming a relationship, including a template for an email or letter (Template Letter for Hospital Leadership) and a template for a slide deck to use during an in-person meeting (Template Deck for Meeting with Hospital Leadership). You will need to find time for that meeting between the PFAC and the relevant people from hospital leadership and/or the people who focus on safety and risk, ideally prior to moving on to Section 6. However, if that is not possible, the meeting can happen after you go through Section 6.

When you get to slide 3 in the main deck, you will be showing the group some of the ideas and suggestions already mentioned during your time together. Before you begin this section, you should have those handy to share back with the group, whether on a hard copy from a flip chart, written on a white board, or chalkboard, or put on a slide that you can add to the slide deck.

Section 5: What could we do about diagnostic quality in our hospital?

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language, please feel free to be conversational and paraphrase as needed.

- Slide 1
 - This is Section 5 of the toolkit, “What could we do about diagnostic quality in our hospital?”.
- Slide 2
 - In previous sections we have talked about patient and family engagement, the diagnostic process and how diagnostic errors occur, about some of the practices that patients, clinicians, and hospitals can use to try to maintain diagnostic quality and we’ve talked about your own personal experiences with diagnosis—whether good or bad. Let’s shift our focus now to what we as a PFAC may want to address in terms of diagnostic quality and safety at our own institution.



Section 5: What could we do about diagnostic quality in our hospital?

- Slide 3
 - At this point, you've all shared some of your personal experiences—whether good or bad--so you may already have some specific ideas for diagnostic quality or safety projects based on those events. During our prior sessions, some of you have already mentioned topics or ideas for projects and I'm sharing those here.
 - Show, either on a slide that has been pre-populated, or on the flip-chart, whiteboard, chalkboard, or something similar, any of the ideas for projects, problems to tackle, or topics to address from the prior sessions.
 - Is there anything based on what is captured here that we could imagine working on together as a PFAC? Or does anyone have additional ideas for the types of things we may want to do?
 - Pause and allow for people to offer ideas; capture any additional ideas on an editable slide or on a flip-chart, whiteboard, chalkboard, or something similar. Let the discussion go on as long as 7 or 8 minutes, but move on as soon as ideas or conversation winds down. If no one speaks up, point out some of the ideas provided in prior sessions and ask the group for their interest in those, and/or provide some prompts to get other ideas or discussion flowing such as:
 - “For example, is there a way to get clearer guidance about “next steps” after a discharge from the emergency room? Or, can staff provide pamphlets or online information to help explain a new diagnosis?”. Allow the conversation to go on for 5-6 minutes, capturing any ideas or topics that arise.
 - Thanks so much for your ideas and thoughts. We are going to talk about other ways to identify projects or activities on the next slide, and we will continue brainstorming as we go.
- Slide 4
 - There may be work related to diagnostic quality ongoing at our hospital. We just need to identify the right information or the right people with whom to connect in hospital leadership. For example, what are the opportunities to be involved in safety and quality activities? What are the current quality or safety concerns? Who from the hospital would be able to talk with us?
- Slide 5
 - Hospitals have different ways to track the quality of care being provided, collect information from the patients and families who are served by the hospital, and respond if some kind of safety event has occurred.
 - One method to collect this information is via a survey provided to patients who have been hospitalized, to understand what their experiences in the hospital. This Survey is called the Hospital Consumer Assessment of Healthcare Providers and Systems, or “H-caps” for short. The HCAHPS survey may reveal opportunities to improve quality or safety of care—including quality and safety of diagnosis. For example, if a frequent theme in the survey information is that people are confused about what they need to



Section 5: What could we do about diagnostic quality in our hospital?

(Slide 5, cont'd) do after they are discharged from the hospital, a PFAC could consider working on a project to help make the process easier and clearer for patients being discharged.

- Another potential source of information is the patient relations department or patient ombudsman at the hospital. Different hospitals call this function different things, but these are the people dedicated to talking to patients and families about concerns, complaints, or suggestions about the care being provided in a hospital. These interactions may happen during an episode of care—while a patient is still in the hospital—or they may be after the fact. In either case, learning from the experiences the patients or families share can be another source for identifying potential projects or opportunities for a PFAC. For example, if a patient had a difficult time getting a diagnosis during their hospital stay, but later learned that the medical team had a good idea of what the issue was—it just hadn't been communicated to the patient or family, that could be an opportunity to develop more effective communication practices, to make sure patients and families know what the medical team thinks is going on, and understands what the plan is for dealing with the diagnosis.
- Information may also be available from the folks at the hospital who directly manage safety or “risk”; these are people who evaluate the systems and practices at the hospital to work to ensure they are as safe as possible. They also get involved when a safety event occurs and a person is harmed. Some of the information this group of people deals with may be confidential or unavailable to share for a number of reasons, but this may be another potential source for insights about what diagnostic quality and safety topics a PFAC may want to address.
- Slide 6
 - For example, at Children’s Hospital of Philadelphia, the PFAC partnered with hospital team members to look at their HCAHPS data—HCAHPS is the survey we just learned about that people who have been discharged from the hospital receive. They noticed that many people reported being confused or feeling a little lost during their hospitalization, not knowing what to expect while a diagnosis was being sought. Based on this information, the PFAC partnered with the hospital team members to develop a guide for people being admitted to the hospital. The guide explains the diagnostic process, equips patients and families with good questions to ask, strategies for accessing important information, and guidance for what to do if they have concerns or worries during the hospital stay. The guide has just recently been implemented, and now the PFAC will partner with the hospital team members to evaluate how effective the tool is.
- Slide 7
 - Another example can be found at Medstar Health, a large health system in the northeast, where patients and families got involved in an awareness and education campaign about sepsis. People who had been affected themselves, or even lost loved ones to sepsis, which is the body’s overwhelming and serious response to infection, helped develop the messaging and materials—including the video that you see in the screenshot here—to urge patients and families to say the words “I suspect sepsis” when

Section 5: What could we do about diagnostic quality in our hospital?

(Slide 7, cont'd) they come to the emergency room with signs or symptoms of this serious condition. Sepsis can be very hard to diagnose because the symptoms can be vague or mimic symptoms from other conditions. By suggesting that the diagnosis may be sepsis, it ensures that sepsis makes it on to the list of differential diagnoses—you may remember that step in the diagnostic process map we reviewed in a prior session—when the clinician or team of clinicians considers what the most likely diagnoses may be. After implementing the campaign, the health system saw a decline in deaths related to sepsis, which is a sign that it is being caught earlier and diagnosed sooner, when it is more likely to be effectively treated and save a patient.

- Slide 8
 - In fact, because other PFACs have done work on diagnostic quality in their institutions, we may be able to learn from what they've done or even implement their ideas here.
 - Many challenges or concerns faced by patients and families are the same, no matter where they are located, so some of the issues tackled by other PFACs may be relevant and valuable to us.
 - In the supplemental materials section of the toolkit, additional examples of PFAC activities are listed. Also, the Institute for Patient and Family-Centered Care or IPFCC, posts examples of successful PFAC initiatives on its website. The Society to Improve Diagnosis in Medicine also highlights effective tools and materials that may be worth considering. Everyone is encouraged to be on the lookout for good ideas from these organizations and other sources.
- Slide 9
 - Please note that in the next few slides, there will be two versions of text to choose from, depending on whether you and/or the PFAC already have relationships with relevant hospital team members. If you already have relationships with relevant hospital team members, your language will be in *italics*. If you need to form relationships with relevant hospital team members, your language will be in **bold**.
 - Let's think for a bit about what next steps we can take to (**start forming**/*tap into the*) relationships with people in our institution who work on safety and risk.
 - One way to (**start/strengthen**) that relationship is to invite risk or safety personnel to one of our meetings; in the supplemental materials of this toolkit, there is a template for an email or letter to invite safety or risk personnel to join us for a discussion, and a suggested agenda and slide deck for that meeting.
- Slide 10
 - On the left is a screenshot of the invitation letter (**we would use**/*we would modify a bit based on our existing relationship*) and on the right are some of the suggested agenda items from the slide deck in the supplemental materials. We would want any of our own PFAC members who feel comfortable doing so, to share any experiences they have had with diagnostic error or any of the concerns or questions they have, and then share some examples we've learned in this toolkit about what other PFACs have done to improve diagnostic quality at their institutions.

Section 5: What could we do about diagnostic quality in our hospital?

- (Slide 10, cont'd) We would want to ask hospital team members how diagnostic quality and safety are handled here--what processes or systems are in place, and what type of information is available for us to see (such as HCAHPS data)? We would also want to know if they have any ideas for a project or topic we could take on.
- Please note that if the hospital team members offer ideas for projects or issues to tackle, you want to capture those and save them; in Section 6 you will be reviewing all of the project and topic ideas that have been mentioned during these sessions, and narrowing down to find the one project the group wants to work on first.
- Slide 11
 - Sharing information about diagnostic quality and safety—and diagnostic error—with hospital leadership is also a good idea. As we discussed earlier, we would share some of the information during our meeting with them, but distributing resources or high-level information in advance of the meeting could be helpful as well. In the supplemental materials section of the toolkit, there are a number of resources that may be helpful to share.
- Slide 12
 - As you can see here, it is a best practice to have folks from the hospital team who focus on quality and safety serve permanently on the PFAC. **We could consider asking some of these individuals to join our PFAC/in our case, we already have those types of people serving on our PFAC so we are on the right track.**
- Slide 13
 - Two key resources provided in the supplemental materials are this article by a leading diagnostic quality researcher that outlines our best estimates at how many people are affected and harmed by diagnostic error, and a pair of guides developed by the Society to Improve Diagnosis in Medicine—they go into a great deal of detail about how PFACs and other patient and family partners can contribute to promoting diagnostic safety at a hospital. One guide is directed at PFACs themselves and the other is directed at hospital leadership. Both resources, in addition to many others, are available in the supplemental materials at the end of the toolkit.
- Slide 14
 - In this section, we discussed what we might be able to do to address diagnostic quality in our own institution. We reviewed some examples of successful efforts by other PFACs and discussed the possibility of adopting or learning from some of those projects. We also discussed the importance of partnering with the safety and risk personnel of the hospital to be able to learn more about how diagnostic quality is managed now, and what opportunities for projects or activities might be.
- Slide 15
 - Thank you so much for your time and participation—this was a great discussion! In the next section, we will continue to explore possible activities for us to undertake and look at some practical tools and resources for moving a project or idea forward.



Section 6: Getting Practical

Section 6 includes Part One, *How can our PFAC partner in diagnostic quality and safety activities?* and Part Two, *Finding our Project!*, and several references to templates and tools, and is focused on really rolling up sleeves and figuring out what project to take on to improve diagnostic safety at your hospital. The first deck explains the Patient Engagement Template, and the second deck is highly interactive, so if your meetings are being held in-person, you will need to capture input and ideas on a flip-chart, whiteboard, chalkboard, or something similar. If you're meeting virtually, you can capture the input on an editable slide. You also will need to have on hand the project suggestions from prior sessions, and any topics or issues that have come up previously from which a project could be formed; these will need to be posted or shared during the brainstorming exercises in part two of this section. During part two, you will also need to conduct a prioritization exercise to generate a short list of project ideas; you may want to familiarize yourself with the instructions for voting and multi-voting before you begin this section.

Section 6, Part One: Getting Practical - How can our PFAC partner in diagnostic quality and safety activities?

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language to use, please feel free to be conversational and paraphrase as needed.

- Slide 1
 - This is Section 6 of the toolkit, “Getting Practical”, and we’ll start with Part One, *How can our PFAC partner in diagnostic quality and safety activities?*
- Slide 2:
 - By now, we have covered a huge amount of information, so let’s pause and just take a look at all that we have learned and done together. We’ve discussed the importance of patient and family engagement and how valuable PFACs can be to their hospitals. We reviewed the diagnostic process, how diagnostic errors occur and how they can be prevented. We learned how to take our own lived experience and turn it into ideas for action. And finally, we examined what’s going on in our hospital with regard to diagnostic safety and quality.
- Slide 3
 - This graphic is just a quick refresher of the What if? Template that you’ve gotten to know and use in Section 4. As a reminder, we use this template as individual patients to think about what we want to improve upon or expand upon from our own care. However, for the next few slides, we are going to transition to a new template—called the Patient Engagement Template, which will help us as a whole group figure out what we can do to contribute to—or lead—a project in diagnostic quality and safety.
- Slide 4
 - In just a little while we will circle back to the ideas we’ve already discussed for projects and work on picking one on which to focus, but first let’s think more specifically about

Section 6, Part One: Getting Practical - How can our PFAC partner in diagnostic quality and safety activities?

(Slide 4, cont'd) what a PFAC would do—how we as PFAC members would lead or contribute to a project on diagnostic quality.

- Slide 5
 - This is the Patient Engagement Template; it is based on the principles of patient engagement developed by the Patient-Centered Outcomes Research Institute, and several tools developed by those involved in creating this Toolkit. It breaks any project idea into three parts—planning, conduct, and dissemination or evaluation. Each of those sections include a number of questions to consider, to help us determine what we can and want to do.

- Slide 6
 - First, in the planning phase, we would need to consider—
 - What is the type of patient or family experience we need for this project?
 - Do we have enough of this experience and if not, where could we find additional partners?
 - Are there other patient safety groups who may be helpful?
 - How can we partner in the creation and design of the plan for this project/effort?

- Slide 7
 - In the “conduct” section—this is once the project is under way, the questions we need to consider are:
 - How can we co-design specific elements of the intervention (i.e., data collection tools, processes, or other items)?
 - As results emerge, how can we help to prioritize meaningful themes and trends, and help to interpret findings?
 - How can we partner in ongoing assessment and adjustment of the project/effort?

- Slide 8
 - And then when the project is well underway or at the end, what would we need or want to do to share the work with others, or evaluate how well the project worked? We would want to think about:
 - How can we help to identify and participate in unique and patient-relevant venues for dissemination?
 - How can we partner in evaluation and improvement of the project/effort?

- Slide 9
 - To get a feel for how the template works, let’s walk through a quick example.

- Slide 10
 - Let’s imagine a PFAC that wants to develop a simple “escalation plan” for patients/families in an emergency situation who do not feel they are getting appropriate



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(Slide 10, cont'd) care. Such escalation pathways exist and have been used in other hospitals and health systems. The PFAC wants to partner with the hospital leadership to develop a simple method to request a conference, evaluate the care, and determine next steps.

- Slide 11
 - Read the information below (from the table on the slide) and then pause to allow for questions or additions from the group; you do not need to capture this input as this is just for learning purposes.
 - Starting with the “Planning” phase, the first step would be to consider the type of patient or family experience needed for this project, which would be patients or caregivers who have had to escalate an emergency issue, or have similar experience.
 - In our hypothetical, there are two people on the PFAC who have relevant experience—in fact they are the folks who suggested the project. One of them has a child who had a ruptured appendix and went septic after a long delay in the diagnosis of her appendicitis; the other person experienced the delayed diagnosis of a heart attack in a hospital that did have an escalation plan, but the family did not know about it or how to access it. These two people can provide very relevant and important insight.
 - However, the PFAC thinks there are other groups that may be helpful, and they plan to reach out to the Society to Improve Diagnosis in Medicine, an advocacy group called Patients for Patient Safety US, and the local patient safety authority to see if there may be a few other patients or caregivers with relevant lived experience to contribute to the project.
 - Lastly, in thinking about how they can partner in the creation and design of the plan for this project/effort, the hypothetical PFAC members identify the major “What ifs?” from their own diagnostic breakdowns and what a valid escalation pathway would have accomplished.
 - The family who experienced the ruptured appendicitis has ideas for how an escalation pathway may have prevented harm to their daughter. The family who experienced the delayed diagnosis of heart attack has suggestions for how to ensure an escalation plan is accessible to patients and families, and widely publicized throughout the hospital.
 - Let’s pause and reflect on what they’ve suggested so far—any questions or thoughts? If you were on this PFAC would you have any additional ideas or considerations?
 - Pause for 3-4 minutes to allow for input/discussion and then move on to the next slide.
- Slide 12
 - Shifting now to the conduct phase, in thinking about how this example PFAC can co-design specific elements of the intervention, the PFAC members want to help design the



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- (Slide 12, cont'd) process for using the escalation pathway to reduce intimidation from staff, eliminate fear of retribution or poorer care, and to ensure access to the pathway is widely known to patients and families. Once the project is underway and results are emerging, they can help to prioritize meaningful themes and trends, and help interpret findings by reviewing the demographics and characteristics of “users” and identify gaps, such as, are there people this process isn't reaching? Are revisions needed?
- Similarly, in thinking about how the example PFAC can partner in ongoing assessment and adjustment of the project/effort, they suggest gathering anonymous input from patient users, and that they would contribute to designing simple surveys to capture that input, and contribute to the analysis of the data.
- Let's pause again and reflect on what the PFAC suggested so far—any questions or thoughts? If you were on this PFAC would you have any additional ideas or considerations?
- Pause for 3-4 minutes to allow for input/discussion and then move on to the next slide.
- Slide 13
 - Finally, for the dissemination and evaluation component, the example PFAC thinks they can help to identify and participate in dissemination by presenting the project at an Institute for Patient and Family-Centered Care conference where so many other PFACs often attend, as well as other convenings of fellow PFACs.
 - In terms of partnering in evaluation and improvement of the project/effort, the PFAC will help develop the anonymous survey described above.
 - Let's pause again and reflect on what they've suggested so far—any questions or thoughts? If you were on this PFAC would you have any additional ideas or considerations?
 - Pause for 3-4 minutes to allow for input/discussion and then move on to the next slide.
 - Great—so that was the Patient Engagement Template, and we'll use it when we identify what project we want to work on together.
- Slide 14
 - Great work—that was the Patient Engagement Template, and we'll use it when we identify what project we want to work on together.
- Slide 15
 - Let's take a minute to review everything we've just covered and shared. We reviewed all of the content and discussions from prior sections and we practiced using the Patient Engagement Template to prepare for our own project planning.



Section 6, Part One: Getting Practical - How can our PFAC partner in diagnostic quality and safety activities?

- Slide 16
 - Thank you so much for your time and participation—this was a great and productive discussion! In the next section, we will roll up our sleeves and figure out what project we are going to take on!

Section 6, Part Two: Getting Practical - Finding our Project!

As a reminder, you will need to have on hand the project suggestions from prior sessions, and any topics or issues that have come up previously from which a project could be formed. Have the suggestions ready to go/compiled prior to starting this section. If you are presenting virtually OR if you have captured notes in slides, please add the slide with your ideas into the PowerPoint (after slide 2) before starting. For the additional brainstorming (beyond what has already been discussed in prior sessions), you will need to work off of a chalkboard, whiteboard, or flipchart, or if you meet virtually, add a blank slide after slide 3 and use in editable mode to capture ideas in real time.

As a reminder, all guidance and facilitator notes will be underlined and separate from the script language. Please note that while the script is the recommended language to use, please feel free to be conversational and paraphrase as needed.

- Slide 1
 - This is the second part of Section 6: *Getting Practical, Finding our Project!* and is our final section of the Toolkit!
- Slide 2
 - We can start by looking at all of the project ideas you've already come up with, as well as issues or topics that have not come up.
 - Point or reference the list on the flip-chart, whiteboard, chalkboard, or something similar, or if you are meeting virtually show a slide with the list.
 - This is the list of what you have produced so far—including ideas from the hospital leadership or other relevant team members. I'll give everyone a moment to review the list.
- Slide 3
 - Now let's take a few minutes to brainstorm any additional ideas that haven't been suggested so far. These can also be issues or topics on your mind based on our prior conversations and what we've covered in the sessions—they don't have to be fully formed project ideas.
 - Capture all of the suggestions on a flip-chart, whiteboard, chalkboard, or something similar, if meeting in person, or if you are meeting virtually use an editable slide and capture the ideas there. Let the brainstorming go on for 4-5 minutes. Next you'll go through a few steps to "clean up" the list, and the goal is to end up with a list that is clear and easy to understand so that the group can begin to prioritize and vote (if needed).



Section 6, Part Two: Getting Practical - Finding our Project!, (cont'd)

(Slide 3, cont'd) Now we are going to flesh out the list a little bit so that we can start to prioritize and identify which project we want to do first. First, let's see if we have any duplicates or ideas that are similar to each other, they could be combined.

- Invite the group to contribute if/as needed, going through the full list (ideas suggested earlier and ideas suggested now) and start to “clean it up” by grouping ideas that are similar they could be combined.
- Next, let's add some details to the ideas that are less formed.
 - For any suggestions that are just issues or topics, ask the group, “What could we do to address this? What type of project might this be?” Add brief notes to each of those ideas. Once the list is ready, move on to the next slide.
- Slide 4
 - If the number of project ideas is small (5 or less), you do not need to vote and you can move to the next exercise (skip to slide 5) which is determining the impact and difficulty of each option. If this is the case, you will say:
 - Since we have a relatively short list, we can evaluate the strengths and weakness for every idea.
 - If the number of project ideas is large (5 or more), use a technique called multi-voting. There is a Multi-voting Guidance included in the supplemental materials, but a shortened version is available below.
 - In multi-voting, everyone is allowed to cast the same number of votes—and the number of votes is 1/3 of the total number of items on the list. So for example, if there are 15 project ideas, everyone can vote for five of the projects—this is just a straight vote, you do not need to rank your choices.
 - Ask everyone to cast their votes publicly or privately as desired. It can be done anonymously, by submitting votes through a digital tool such as sli.do (<https://www.slido.com>) or by voting on paper ballots. It can also be done publicly, through a show of hands or other interactive group activities such as placing a sticker or making a mark next to the items a person wants to vote for on a chalkboard or whiteboard.
 - Next, eliminate choices that received fewer votes, but the number that gets eliminated depends on the size of the group voting.
 - For less than 5 PFAC members: eliminate options with less than 2 votes.
 - 6 to 15 PFAC members: Eliminate options with less than 3 votes.
 - For more than 15 PFAC members: Eliminate options with less than 4 votes.
 - If there is a clear winner or short list (3-4) of winners, stop there. If not, repeat steps 1-4 until there is a winner or short list of winners.



Section 6, Part Two: Getting Practical - Finding our Project!, (cont'd)

- Slide 5
 - Thank you for working through that brainstorming and prioritization process! All of the ideas were great and again, just because they did not make it to the top of the list does not mean they are gone—we will keep them and can circle back to them at a later time.
 - Now with our shortened, prioritized list let's spend a little time thinking about the impact and the potential difficulty of each idea. The ideal project is high impact, but not overly difficult. This does not mean we cannot take on difficult projects, but it will be helpful to see the ideas plotted on this quadrant. So, let's take each idea and think about...how impactful does this project have the potential to be? And how difficult might it be to do--what would the barriers be?
 - Go through each of the project ideas and ask these two questions. Depending on the discussion and answers, plot the project idea where it best fits in the quadrant. If it is a virtual meeting, you can make this slide editable and add the project ideas right into the table. If it is an in-person meeting, you can draft a simple version of the quadrant table and add the project ideas to it on a flip-chart, whiteboard, chalkboard, or something similar.
 - Once you have worked through the exercise, if there is a clear "winner" you can move on to the next slide. If there is not a clear winner, continue to discuss and again reassure the group that just because a project is not the winner this time, it doesn't mean the group can't return to it.
- Slide 6
 - Now that we have decided on the first project we are going to work on, let's get into some more specifics. This table is a simplified version of a tool developed for Quality Improvement projects by Johns Hopkins University. It prompts us to consider distinct aspects of our idea.
 - The first step is to be very specific. What exactly is our goal and how are we going to get there? What are the activities we will undertake and the short-term goals (or "objectives") we plan to accomplish along the way?
 - We also need the project to be measurable. Are the objectives measurable? How will we know if the changes resulted in improvement?
 - Similar to what we discussed with the impact and difficulty quadrant, is achievability. Is this project doable in the time we have? Are we trying to do too much? Should we do more?
 - Furthermore, is this project relevant and realistic? Do we have what we need—the time, the right people, the financial support, or other things—to accomplish this task?
- Slide 7
 - To see how these questions work in action, this is the same table—divided into two slides—with an example provided to demonstrate how these questions may be



Section 6, Part Two: Getting Practical - Finding our Project!, (cont'd)

- (Slide 7, cont'd) answered. In this case, a PFAC wants to develop a project around medication safety, and so in the description of the project, they clearly list the interventions they would like to develop or test in the project: taking a picture of all medications or bringing a bag of all current medications to the hospital, using an iPhone or other app to help keep track of what medications are used, and/or having easy access to an online pharmacy portal that shows all medications and doses.
- The PFAC describes their goals and objects like this: Our goal is to reduce medication-related diagnostic issues. We will do this by a) compiling a list of approaches that patients and families can use to better track and report what medications are being used, and b.) disseminating information about these approaches to patients who are part of this hospital community, and those arriving at the emergency department.
- To measure the interventions used in the project, the PFAC plans to partner with hospital leadership to understand whether the rate of medication-related diagnostic issues changed after implementation of the resources.
- Slide 8
 - The table continues on this slide, with the section on achievability. Here the PFAC states they believe they can work with their assembled partners to compile a list of tested/trusted approaches, and implement the dissemination campaign after the list is compiled.
 - In terms of relevance and assessing how realistic the project is, the PFAC indicates they need clinical and pharmacy partners to help confirm the best approaches to suggest for tracking and reporting on current medications and that they will work with the hospital to identify those partners. They also need support and interaction with hospital safety and risk personnel to help track impact of the project on the rate of medication-related diagnostic issues.
 - Lastly, in thinking about timeliness, the PFAC acknowledges they'll need to work closely with the hospital team to determine timeline, but they believe compiling the list of approaches could be done in about 6 months, with implementation of the dissemination happening in the 6 months after the list is compiled.
- Slide 9
 - Now it's our turn. Taking the project idea we have prioritized, let's fill out the segments of this table to get more specific with our project idea.
 - Invite the group to contribute to the blank table starting with the more specific description of the project, and capture what the group provides directly into the slide by putting it in editable mode (regardless of whether you're meeting in person or virtually).
 - Let's start with our project idea, describing it with the same level of detail as the example.



Section 6, Part Two: Getting Practical - Finding our Project!, (cont'd)

- (Slide 9, cont'd) Next, what exactly is our goal and how are we going to get there? What are the activities we will undertake and the short-term goals (or “objectives”) we plan to accomplish along the way?
- For the next section, are our objectives measurable? How will we know if the changes resulted in improvement?
- What about achievability? Is this doable in the time we have? Are we trying to do too much? Should we do more?
- And lastly, let’s get realistic. Do we have what we need—the time, the right people, the financial support, or other things—to accomplish this? What—and who—do we need?
- Slide 10
 - With this more specific vision of our project idea fleshed out, let’s return to the Patient Engagement Template we learned about earlier in this section and think more specifically about all the things we as the PFAC can bring to this work.
 - Invite the group to contribute to completing the template, and capture what the group provides directly into the slide by putting it in editable mode (regardless of whether you’re meeting in person or virtually).
 - Starting with planning:
 - What is the type of patient or family experience we need for this project?
 - Do we have enough of this experience and if not, where could we find additional partners?
 - Are there other patient safety groups who may be helpful?
 - How can we partner in the creation and design of the plan for this project/effort?
 - Thinking more now about once the project is underway:
 - How can we co-design specific elements of the intervention (i.e., data collection tools and processes)?
 - As results emerge, how can we help to prioritize meaningful themes and trends, and help to interpret findings?
 - How can we partner in ongoing assessment and adjustment of the project/effort?
 - And lastly, when we want to share information about this work or evaluate its strengths and weaknesses:
 - How can we help to identify and participate in unique and patient-relevant venues for dissemination?
 - How can we partner in evaluation and improvement of the project/effort?

Section 6, Part Two: Getting Practical - Finding our Project!, (cont'd)

- Slide 11
 - First, let's take a moment to congratulate ourselves and each other on all of the work we have just undertaken! This was a great deal of content, and everyone put in so much work to get here. Of course, this is the beginning and not the end—now we can use some of what we have learned and practiced.
 - Our next step is to share our ideas with relevant team members from the hospital and work with them, identifying additional partners and project team members, or necessary resources. Starting now and throughout the life of the project, let's remember we can consult the supplemental materials from the toolkit to use for additional guidance or ideas.
- Slide 12
 - We have come to the end of the final Section, so let's pause and review what we have done.
 - We reviewed and brainstormed project ideas.
 - We identified one project to tackle.
 - We considered project planning and evaluation.
- Slide 13
 - Thank you so much for your time and participation—not only with this last section but with all of the material we covered in this toolkit to leverage patient engagement to address diagnostic safety and quality.



Supplemental Materials Description and Information

Society to Improve Diagnosis in Medicine Patient Toolkit for Diagnosis

This is a “by patients, for patients” guidance for those navigating the diagnostic process. It helps patients and families organize and plan for clinic visits, tests, and other activities, and provides a number of suggested questions and strategies for trying to obtain a timely and accurate diagnosis.

“What if?” Template

This tool was developed through a project at the Society to Improve Diagnosis in Medicine, to help patients and families document their diagnostic experiences and identify key learning objectives or potential ideas for improvements to the diagnostic process.

Template Letter for Hospital Leadership

This letter can be modified for your PFAC’s use in communicating with and inviting hospital leadership to a meeting to discuss diagnostic quality and opportunities for diagnostic quality projects at your institution.

Template Deck for Meeting with Hospital Leadership

This template for a slide deck can be used to guide the discussion between your PFAC and the leadership at your hospital. It includes ideas for organizing the discussion, inviting PFAC members to share their concerns and ideas about diagnostic quality, and learning from leadership about what diagnostic quality efforts may already be underway.

Patient Engagement Template

This tool is based on the principles of patient engagement developed by the Patient-Centered Outcomes Research Institute, and modified from several tools developed by those involved in creating this Toolkit. It breaks any project idea into three parts—planning, conduct, and dissemination or evaluation. Each of those sections include a number of questions to consider, to help you determine what you can and want to do to bring the lived experience of patients and families to the forefront of an activity.

Evaluating Impact and Difficulty Matrix

This is a simple plotting tool to allow your PFAC to organize project ideas, assess their potential impact versus their potential difficulty, and determine which project you should work on first.

Multi-Voting Guidance

Multi-voting is a practice for helping a group narrow down from a large list of ideas to a small list of ideas, or even down to a single idea. It allows all participants to participate in the voting, and slowly eliminates the ideas that receive fewer votes, until there is general consensus about which project or projects to focus on.

Supplemental Materials Description and Information, (cont'd)

Project Plan Template

This template is modified from a Quality Improvement (QI) project template developed by Johns Hopkins University. It is intended to help your PFAC think more comprehensively about taking on a project, and all of the timing, logistical, leadership, resource, and other considerations.

Patient and Family Advisory Council Exemplars

While not an exhaustive or complete list by any means, this is a short list of PFACs who have been celebrated and recognized for their important efforts to improve quality and experience of care at their hospitals.

Glossary

The glossary includes a list of commonly used acronyms, a short number of engagement- and diagnosis-related terms, and links to external glossaries with a wealth of terms and information for your PFAC.

Agency for Healthcare and Research Quality (AHRQ) Engaging Patients To Improve Diagnostic Safety Toolkit Roadmap

This is a potential resource for PFACs seeking to work on diagnostic quality in their hospitals; it provides guidance for both “Type A” or personal engagement as well as “Type B” or system-level engagement (if these terms are unfamiliar please see the Glossary).

Compendium of Diagnostic Quality Resources

This list of resources and research is not meant to be exhaustive but it provides a significant amount of information as well as proposed strategies and tools for addressing diagnostic quality in the clinical setting.

