

# SIDM2022 Patient Summit

## Conference Proceedings



SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

## ACKNOWLEDGMENTS

Our most sincere thanks to Charity Watkins, PhD, Jennifer Andrashko, MSW, and Wanda Tswago, our three patient experts, who were brave enough to share their very personal and traumatic diagnostic error stories in the spirit of education and collaboration. We would also like to thank Bethany Sabol, MD, Carl Berdahl, MD, and Denise Connor, MD, for sharing their clinical, diagnostic quality, and health equity expertise to shape and guide our workshop.

Our very special thanks to the two Patient Summit Co-Chairs, Helene Epstein and Stacy Hurt, and to the members of SIDM's Patient Engagement Committee who contributed to the planning and execution of the event, Dan Berg, David Meyers, Gwen Mayes, and Kathy McDonald.

Thank you to all of the expert discussants and participants who contributed and shaped the outcomes of the day.

We are also grateful to SIDM team members Aubrie Killeen-McKernan, Jeremiah Smith, Marie Jaffe, and Suz Schrandt, for bringing this event to fruition.



# PATIENT SUMMIT CONFERENCE PROCEEDINGS

EXECUTIVE SUMMARY

# PATIENT SUMMIT CONFERENCE PROCEEDINGS

## EXECUTIVE SUMMARY

Each year, the Society to Improve Diagnosis in Medicine (SIDM) brings together hundreds of individuals and groups from the diagnostic safety community to the Diagnostic Errors in Medicine conference to share best practices, galvanize partnerships, and collectively advocate to move the field forward to keep patients and families safe from harm. A hallmark of the conference is the Patient Summit, a “by patients, for patients” event, created and hosted by those personally affected by diagnostic error. The 2022 Patient Summit was a radical departure from prior years, becoming an opportunity to demonstrate the unparalleled power of patients as partners in diagnostic quality innovation.

The idea for this year’s Patient Summit came from a patient safety advocate familiar with a concept from the tech world known as a “hackathon”. While hackathons typically involve many small groups of cross-discipline innovators competing for a prize against the same problem, the hackathon concept was transformed into three workshop teams, with different areas of focus. All were oriented around the same diagnostic error landscape and cases, and all used the same rules and processes. The goal was for each breakout workshop to brainstorm ideas, galvanize around a single idea, and then flesh out the idea to present back to the main room in the final session. In the final session, a vote was to take place, and the winning idea could be submitted to SIDM’s [DxQI Seed Grant](#) program for funding.

For the Summit’s clinical and patient experience focus, we identified missed and delayed diagnoses contributing to the devastating and unacceptably high rates of maternal mortality and morbidity in the United States. Touching on multiple types of diagnostic breakdowns such as cognitive errors (including those related to race, ethnicity, and gender), system failures, educational and knowledge gaps, and problematic culture/team dynamics, the selected diagnostic error case studies engendered a rich discussion and provided fertile ground on which to develop and debate potential solutions.

In the opening session, three patient experts, Charity Watkins, PhD, Jennifer Andrashko, MSW, and Wanda Tswago, shared their diagnostic error stories, mapped to the National Academies’ diagnostic process diagram. Although the women come from different parts of the country, have different backgrounds, and experienced different diagnostic errors related to their pregnancies, there were several commonalities across the three cases. All experienced cardiovascular conditions either during pregnancy and/or following delivery. All experienced having their symptoms and concerns dismissed, being made to wait several hours for care despite presenting with emergent symptoms, and getting to a dangerous state of health before finally receiving an accurate diagnosis and necessary treatment. Each patient talked about where the breakdowns occurred in their diagnostic journeys and provided important building blocks for the Summit participants to use as they prepared for the workshopping portion of the event.

Following the three case presentations, a panel of clinicians including Bethany Sabol, MD, Carl Berdahl, MD, and Denise Connor, MD, provided their reactions to the powerful stories as well as context about the greater landscape of maternal health and health equity in the United States. These speakers further prepared the Summit participants to transition into the workshop portion of the day, by offering several potential areas in need of solutions. At the conclusion of all of the speakers, participants were provided with instructions for the remainder of the workshop.

The participants were asked to self-divide into one of three breakout rooms, each exploring a solution focused on a different aspect of the case. One room explored solutions that patients and families may themselves use, another room explored solutions that would be clinician-facing and/or clinician-used, and the last room explored solutions that are targeted more at the system level, whether that is hospital, health system, or another construct of “system”. All stakeholder types were present in all rooms, and each room had a team of people dedicated to guiding the exercise and moving the group forward. These groups included a lead facilitator, a lead scribe, and a group of expert “discussants”, each with unique expertise, who were pre-prepared to offer ideas for solutions and contribute to the discussion and solutions-generation. Critically, the expert patient discussant in each room was one of the women whose diagnostic error stories were provided as the foundation on which solutions were to be generated. Although there was a team “leading” the work, the idea was that the entire population in each room comprised the innovation team, with no division based on academic or professional titles.

Each of the three breakout rooms were designed to follow the same schedule and approach for brainstorming, multi-voting, and solution-creation. The brainstorming began with a 90 second individual rapid ideation session on paper, and then transitioned to round robin brainstorming, without debate or discussion on a given idea. Once the full complement of ideas was captured and thematically grouped in an editable PowerPoint being broadcast at the front of the room, each room transitioned to voting. Once selected, the winning idea was then more fully fleshed out using the SIDM DxQI Seed Grant scoring criteria (available in the appendix at the end of this document).

In the final portion of the Summit, all participants reconvened in the main room for a report out on the nominated solution from each breakout room. Designated spokespeople for each breakout room described their proposed solution with enough detail to allow the room to vote on which solution idea should receive SIDM DxQI Seed Grant funding. The three proposed solutions were:

- A suite of educational support tools and resources for patients/families, initiated through a community-driven, trust-building process, and commencing with an emergency room sign campaign and collection of peer-to-peer videos to encourage women and pregnancy-capable individuals and their families to speak up when they are concerned complications have occurred.
- An electronic medical record “flag” to alert clinicians of potential complications following pregnancy, and a series of required activities including consults from maternal and peri- and postpartum clinical experts.

- An updated coverage policy that defines postpartum as a two-year period of time following pregnancy and requires consult (in person or remotely) with a clinician who is an expert on potential maternal postpartum health issues for every postpartum patient within the two-year redefined period.

It was agreed across all Summit participants that all three of the proposed solutions were essential, and most notable amidst the conversations and report-outs was the incredible similarity between the rooms. Despite being divided into rooms tasked to focus on three different focal points—solutions that are patient-facing, clinician-facing, and at the system-level, each group surfaced the need for all stakeholder types to be involved in the creation and execution of the solution, and each group surfaced that their identified solution would not and could not work in isolation. One of the Summit participants made a motion to suspend the vote, and instead task SIDM and those interested Summit participants to move forward with a concept that combines and integrates the three solutions into a single coordinated approach. Those interested in partnering with SIDM to support and foster this work were invited to create a work group to pursue funding—including SIDM DxQI Seed Grant funding—and advance the effort.

This output, even in its current nascent form, is a fitting and successful end to what was a dynamic and diverse event. The goal of the Summit, aside from the generation of important ideas, was to cement the critical importance of including patients alongside clinicians, researchers, and others in efforts to innovate. The patient participants in the Summit certainly brought that truth to bear, and the clinician, researcher, and other healthcare stakeholders involved further demonstrated the value and necessity of bringing a variety of perspectives and experiences together to achieve optimal creativity and viability.



# PATIENT SUMMIT CONFERENCE PROCEEDINGS

INTRODUCTION AND CONCEPT

# PATIENT SUMMIT CONFERENCE PROCEEDINGS

## PATIENT SUMMIT: A HISTORY

In 2022, diagnostic error once again made ECRI's [top ten list](#) of patient safety concerns, and with good reason. Roughly 12 million Americans experience diagnostic errors in the ambulatory care setting each year, with 40,000 – 80,000 Americans dying from diagnostic errors in the inpatient setting. It is estimated that everyone will experience at least one diagnostic error during their lifetimes. Despite all of this terrifying data, there is no specific federal entity committed to studying or addressing diagnostic error—there is no “Diagnosis Institute” within the National Institutes of Health. But through the Society to Improve Diagnosis in Medicine (SIDM)’s leadership and energy, the essential need for accurate and timely diagnosis is becoming more widely acknowledged.

Each year, SIDM brings together hundreds of individuals and groups from the diagnostic safety community to the Diagnostic Errors in Medicine conference to share best practices, galvanize partnerships, and collectively advocate to move the field forward to keep patients and families safe from harm. A hallmark of the conference is the Patient Summit, a “by patients, for patients” event, created and hosted by those personally affected by diagnostic error. The 2022 Patient Summit was a radical departure from prior years, becoming an opportunity to demonstrate the unparalleled power of patients as partners in diagnostic quality innovation.

## FROM DESCRIBING PROBLEMS TO CREATING SOLUTIONS

The idea for this year’s Patient Summit came from a patient safety advocate familiar with a concept from the tech world known as a “hackathon”. A traditional hackathon is a collaborative cross-discipline competition seeking innovative solutions to a posed issue. While the Patient Summit is not necessarily a candidate for programming or coding technology-based solutions, the multi-stakeholder

and multi-dimensional approach of a hackathon made it a compelling model on which to build a solutions-generation workshop in the area of diagnostic quality and safety.

“At triage, my blood pressure was 200/180 and I had all the classic signs of a heart attack, but I was sent back to wait for several more hours in the ER.”

--Wanka Tswago, sharing her attempt to get medical attention for her heart attack

While hackathons typically involve a small group of innovators, the Patient Summit is attended by a large number of patients, clinicians, researchers, and others committed to diagnostic excellence. To accommodate this large number of participants, the hackathon concept was transformed into a group of parallel workshops, all oriented around a collection of related diagnostic error cases, and all using the same rules and processes to generate a set of potential solutions. The goal was for each breakout workshop to brainstorm ideas, galvanize around a single idea, and then flesh out the idea to present back to the main room in the final session.



In the final session, a vote was to take place, and the winning idea could be submitted to SIDM's DxQI Seed Grant program for funding.

For the Summit's clinical and patient experience focus, we identified missed and delayed diagnoses of cardiovascular conditions during pregnancy and following delivery as a complex body of diagnostic errors, and just one of the contributors to the devastating and unacceptably high rates of maternal mortality and morbidity in the United States. Touching on multiple types of diagnostic breakdowns such as cognitive errors (including those related to race, ethnicity, and gender), system failures, educational and knowledge gaps, and problematic culture/team dynamics, the selected diagnostic error case studies engendered a rich discussion and provided fertile ground on which to develop and debate potential solutions.

#### AGENDA AND CONSTRUCT

As shown in the agenda in Figure 1-1, the summit participants all began in the same main session, during which an esteemed panel of patient advocates shared their diagnostic error stories, mapped to the National Academies of Medicine [Diagnostic Process Map](#). These multi-faceted diagnostic error stories in the maternal morbidity and mortality space, served as the collective case study for the rest of the workshop. In that same session, an obstetrics and gynecology physician, an emergency room physician and diagnostic quality scholar, and a hospitalist and physician expert in health equity, shared perspectives on the case studies presented, including insights about prevalence and contributing factors to such errors, and most importantly, suggested areas for exploration in our solutions-generation breakouts.

Figure 1-1, Summit Agenda

Summit Agenda	
<b>Welcome</b> – Dr. Jennie Ward-Robinson	8:00 am – 8:05 am
<b>Overview of Format-&amp; Introduce Topic</b> - Suz Schrandt	8:05 am – 8:10 am
<b>Presentation of Cases</b>	8:10 am – 8:40 am
<b>Q&amp;A related to Patient Cases</b> – Moderator Suz Schrandt	8:40 am – 8:50 am
<b>Introduce Landscape Experts</b> – Helene Epstein	8:50 am – 8:55 am
<b>Perspectives on Maternal Mortality and Morbidity</b>	8:55 am – 9:25 am
<b>Overview of the Breakout Sessions</b> – Suz Schrandt	9:25 am – 9:30 am
<b>Break</b> – Transition into breakout rooms	9:30 am – 9:40 am
<b>Breakout Sessions</b>	9:40 am – 11:10am
<b>Break</b> – Transition back to main room	11:10 am – 11:20am
<b>Report Outs</b> - All	11:20 am – 11:55 am
<b>Wrap up and vote on best solution</b> – Helene Epstein	11:55 am – Noon

The participants—and speakers—then divided into three breakout rooms, each exploring a solution focused on a different aspect of the case. One room explored solutions that patients and families may themselves use, another room explored solutions that would be clinician-facing and/or clinician-used, and the last room explored solutions that are targeted more at the system level, whether that is hospital, health system, or another construct of “system”. The participants were divided up such that all stakeholder types were present in all rooms, and each

“He was describing the symptoms of a panic attack; I know because I diagnose panic attacks in my clinical practice. I was not having a panic attack, I was having trouble breathing.”

--Jennifer Andrashko, sharing the nurse's reaction to her complaints of shortness of breath

room had a team of people dedicated to guiding the exercise and moving the group forward. This group included a lead facilitator, a lead scribe, and a group of expert “discussants”, each with unique expertise, who were pre-prepared to offer ideas for solutions and contribute to the discussion and solutions-generation. Although there was a team “leading” the work, the idea was that the entire population in each room comprised the innovation team, with no division based on academic or professional titles.

Each of the three breakout rooms were designed to follow the same schedule and approach for brainstorming, multi-voting, and solution-creation. The brainstorming began with a 90 second individual rapid ideation session on paper, and then transitioned to round robin brainstorming, without debate or discussion on a given idea. Once the full complement of ideas was captured and thematically grouped in an editable PowerPoint being broadcast at the front of the room, each room transitioned to voting.

Voting for the “best” idea was to be informed by five key characteristics for innovative ideas, determined by the Patient Summit planning team and influenced by the SIDM DxQI Seed Grant funding selection criteria. The characteristics for a viable, innovative idea are outlined in the Figure 1-2 below on the following page.

Voting was intended to be conducted using a multi-voting process, with selections communicated via sli.do technology (a mechanism for participants to vote using their cell phones). The concept for multi-voting is every person selects their top 1/3 of the ideas presented, and items with less than 5 votes after the first round are eliminated. The process repeats until there is a clear winner.

Once each room catalyzed around a single solution idea, the last activity began; discussing and fleshing out the details of the idea according to the review criteria for the SIDM DxQI Seed Grant program. The table on page 12 outlines the review criteria, and the groups were asked to articulate how the idea would be developed to be responsive to each element.

Finally, during the last portion of the summit, each breakout room group was invited back to the main room to report out on their solution ideas. After presentation of the ideas, the goal was to take a simple vote, and identify the “winning” idea for potential SIDM Seed Grant funding.

Figure 1-2, Innovation Criteria

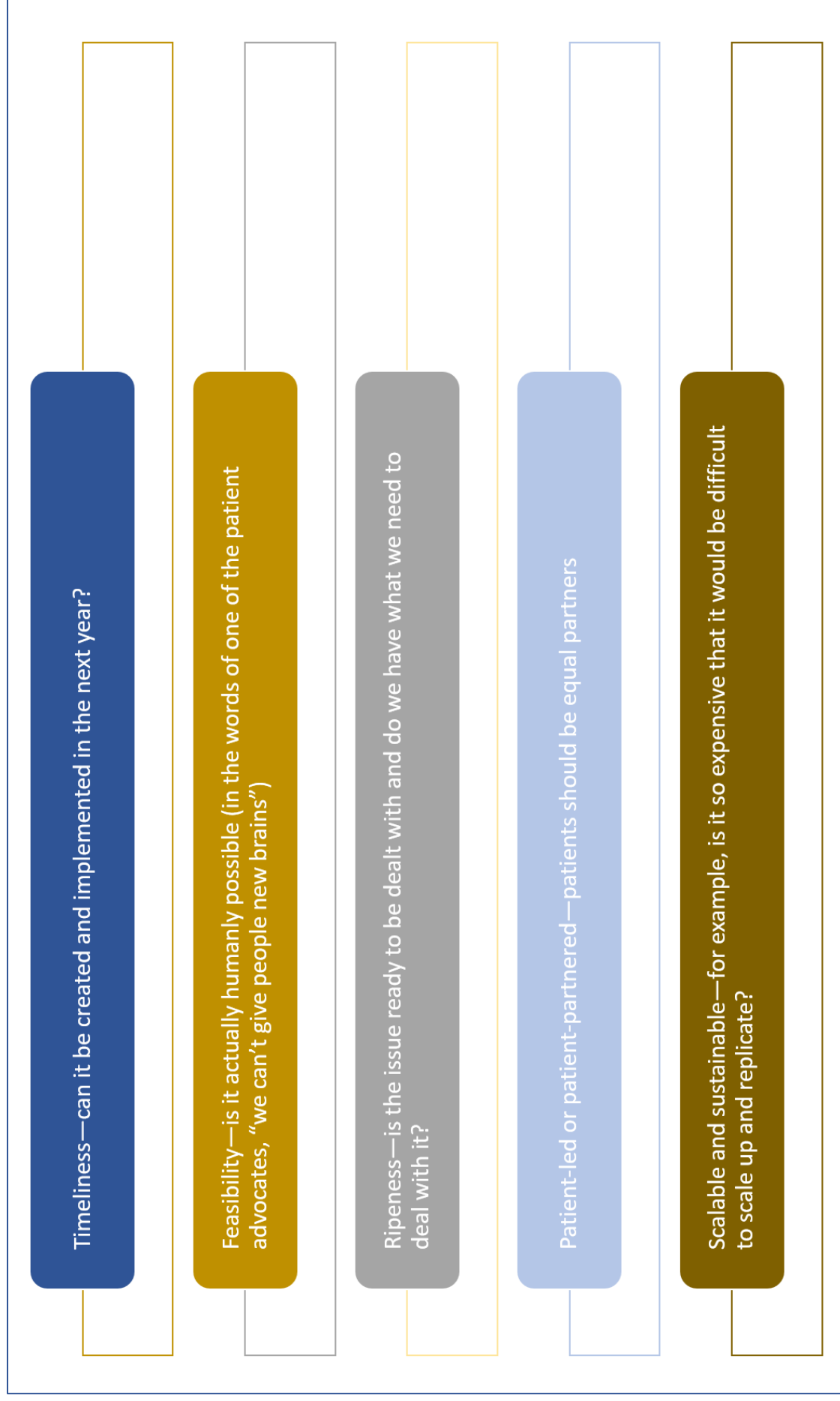


Table 1-1, SIDM DxQI Seed Grant Review Criteria (Amended)

Review Criteria	Group Response
What is the location for the intervention?	
What is the specific problem the intervention aims to solve	
We need a clear description of the intervention and rationale for the intervention	
To what segment or segments of the Diagnostic Process would this intervention apply?	
What is the population to whom this intervention would apply?	
How would the intervention be created?	
How would the intervention be implemented?	
What are the barriers to success we can foresee and how might we address them?	
How would the intervention be evaluated for effectiveness? How would we know it is working?	
If effective, how would the intervention be scaled or expanded for greater uptake and use?	



# PATIENT SUMMIT CONFERENCE PROCEEDINGS

OPENING SESSION

## PROCEEDINGS: OPENING SESSION

After a welcome by SIDM's CEO, Jennie Ward-Robinson, PhD, SIDM's Senior Patient Engagement Advisor Suz Schrandt explained the layout of the day, and gave a brief overview of the three breakout rooms and the task and focus for each one. She then introduced the three patient advocates around which the rest of the day would be organized. Each speaker brought their lived experience of significant diagnostic error related to or immediately following pregnancy, and shared the details and learnings from their stories on which the workshop activities would be based, all in the spirit of multi-stakeholder collaboration to tackle real-world problems.

### *Patient Advocate Case Studies*

Charity Watkins, PhD, a three-time graduate of UNC Chapel Hill, is a tenure-track assistant professor in the Department of Social Work at North Carolina Central University. Charity's research interests include parenting practices that promote academic resilience among low-income African American families. She has also explored racial disparities in cardiovascular



disease with a special focus on heart conditions experienced by Black women following pregnancy and childbirth.

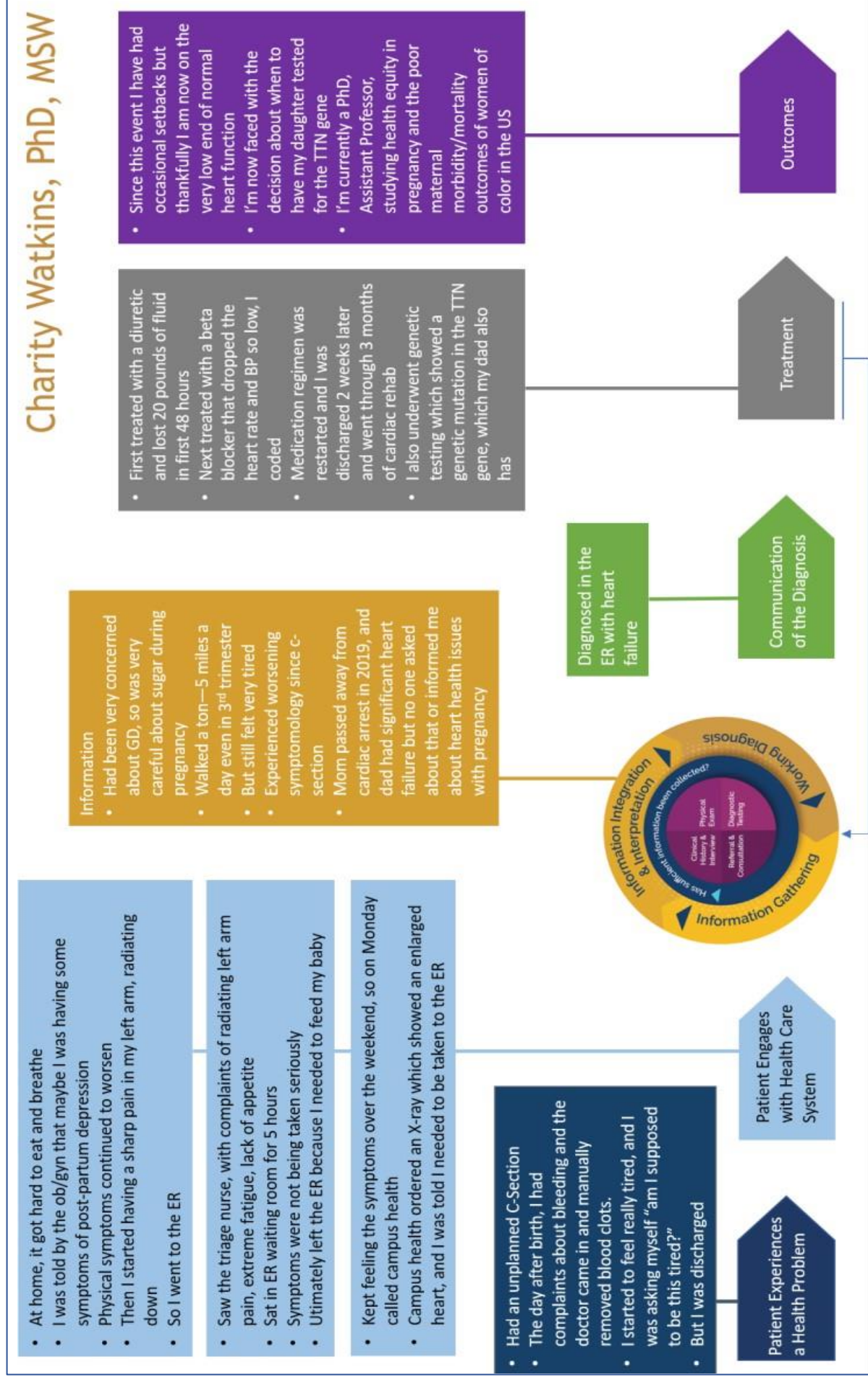
Charity's diagnostic error began shortly after the birth of her daughter, when she began to feel immense fatigue, prompting her to ask her clinical team "Am I supposed to feel this tired?" She was assured that this was normal and that if it persisted, perhaps she should be evaluated for post-partum depression. When she began having radiating pain from her left arm she knew to be concerned about a cardiac event and went to the ER. She was left to wait for five hours in the waiting room, and had the sense that her symptoms were not being taken seriously. Eventually, she left and went home, needing to nurse her newborn who was only days old.

After not improving over the weekend, Charity sought care the following Monday at the campus health center where a chest x-ray was performed, revealing a significantly enlarged heart. She was urgently admitted to the hospital and ultimately diagnosed with heart failure. It was later discovered that Charity carries a genetic mutation to the TTN gene that plays a role in cardiovascular risk. Her father also carries the gene and her mother died of a cardiac arrest in 2019, but she was never asked about her family history during her pregnancy. Charity urged the Patient Summit participants to focus on racial and gender inequities in care, pointing to how many times during her diagnostic journey she was disregarded or ignored. She felt that the familiarity she had with the campus health team ultimately played a role in saving her life and she noted the role that social workers can play in such care settings as advocates and navigators for patients who are being dismissed.

Charity's diagnostic story is mapped to the National Academies of Medicine Diagnostic Process Map on the following page.



Figure 1-3, Charity's story as outlined on the National Academies of Medicine Diagnostic Process Map





Wanda Tswago, a trained medical technologist and proud mother of two, is a heart attack survivor and a tireless advocate for women's heart health. She is a WomenHeart Champion, (class of 2003), and through this work she educates the public, patients, and the medical community about the widespread issue of delayed and missed diagnosis of heart disease in women.

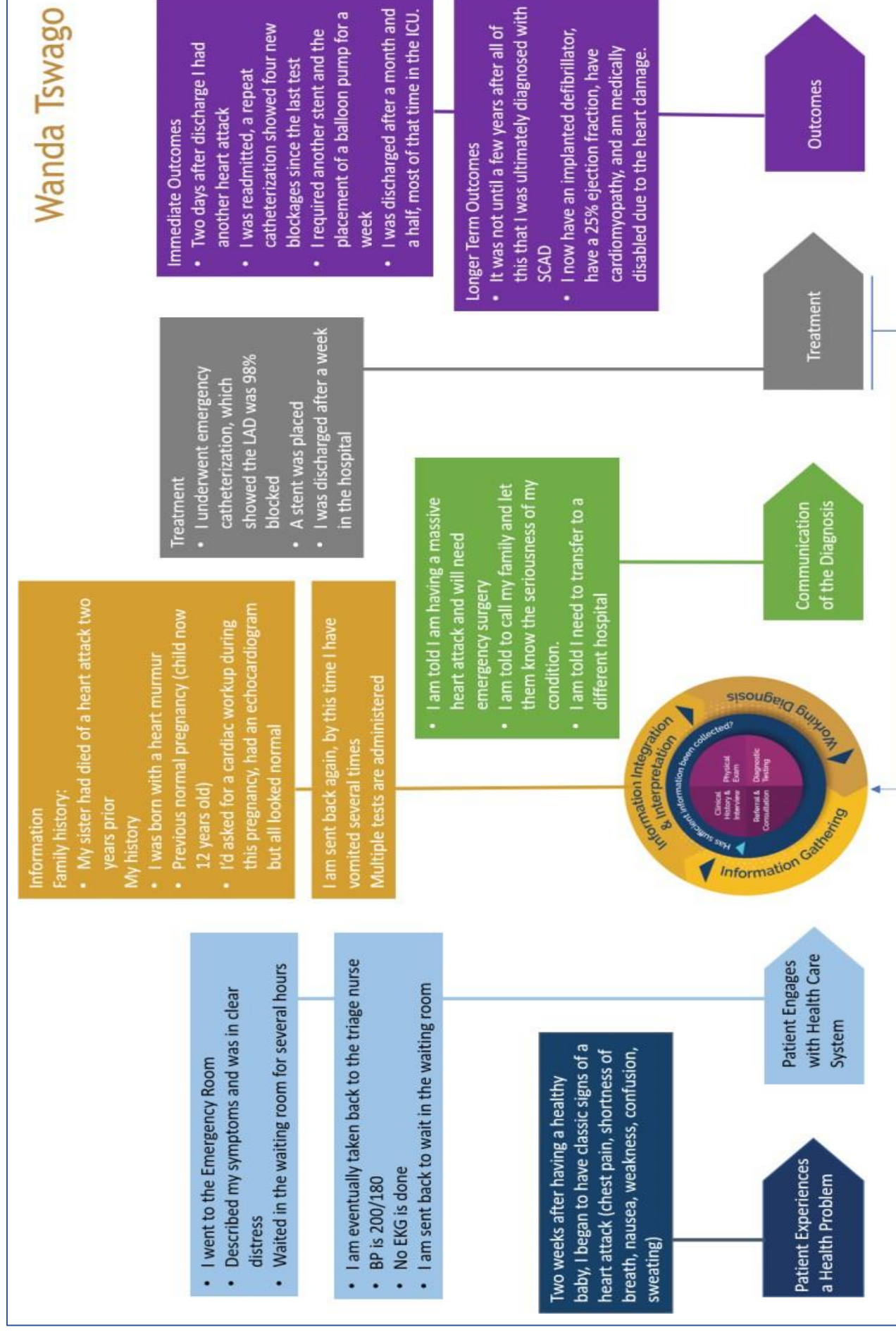
Wanda's series of diagnostic errors began two weeks after she gave birth to her daughter when she began having classic signs of a heart attack including chest pain, confusion, sweating, nausea, shortness of breath, and weakness. Like Charity, she was made to wait for several hours in the ER, even after being evaluated and shown to have a blood pressure of 200/180 at which point no EKG was performed. It was only after several more hours, and episodes of vomiting, that she was finally placed in a room to undergo testing. All of a sudden, as Wanda shares, "Everyone went into a panic." She was told she was having a massive heart attack and that she needed to notify her family of the seriousness of her condition. At this point, she was transferred to a different hospital with more capabilities to treat her.

Wanda underwent emergency catheterization, which showed the left anterior descending (LAD) artery was 98 percent blocked and a stent was placed. She was discharged about a week after the procedure, but soon had another heart attack. Upon readmission, another catheterization showed four previously unseen blockages, and another stent was placed along with a balloon pump. She remained in the hospital, primarily in the Intensive Care Unit, for a month and a half. Years after these two events, she was finally diagnosed with SCAD or spontaneous coronary artery dissection. Wanda now has an implanted defibrillator and a 25% ejection fraction (a measurement of heart function; a "normal" ejection fraction is 50% - 75%). She has cardiomyopathy and is medically disabled due to the heart damage. Wanda shared not only her story, but that of her sister who she lost to a heart attack two years prior to her own cardiac event. She implored the Patient Summit participants to hone in on the critical importance of having a family member or other advocate in place who knows your history and your family history, and can help push for urgent, appropriate care.

Wanda's diagnostic story is mapped to the National Academies of Medicine Diagnostic Process Map on the following page.



Figure 1-4, Wanda's story as outlined on the National Academies of Medicine Diagnostic Process Map





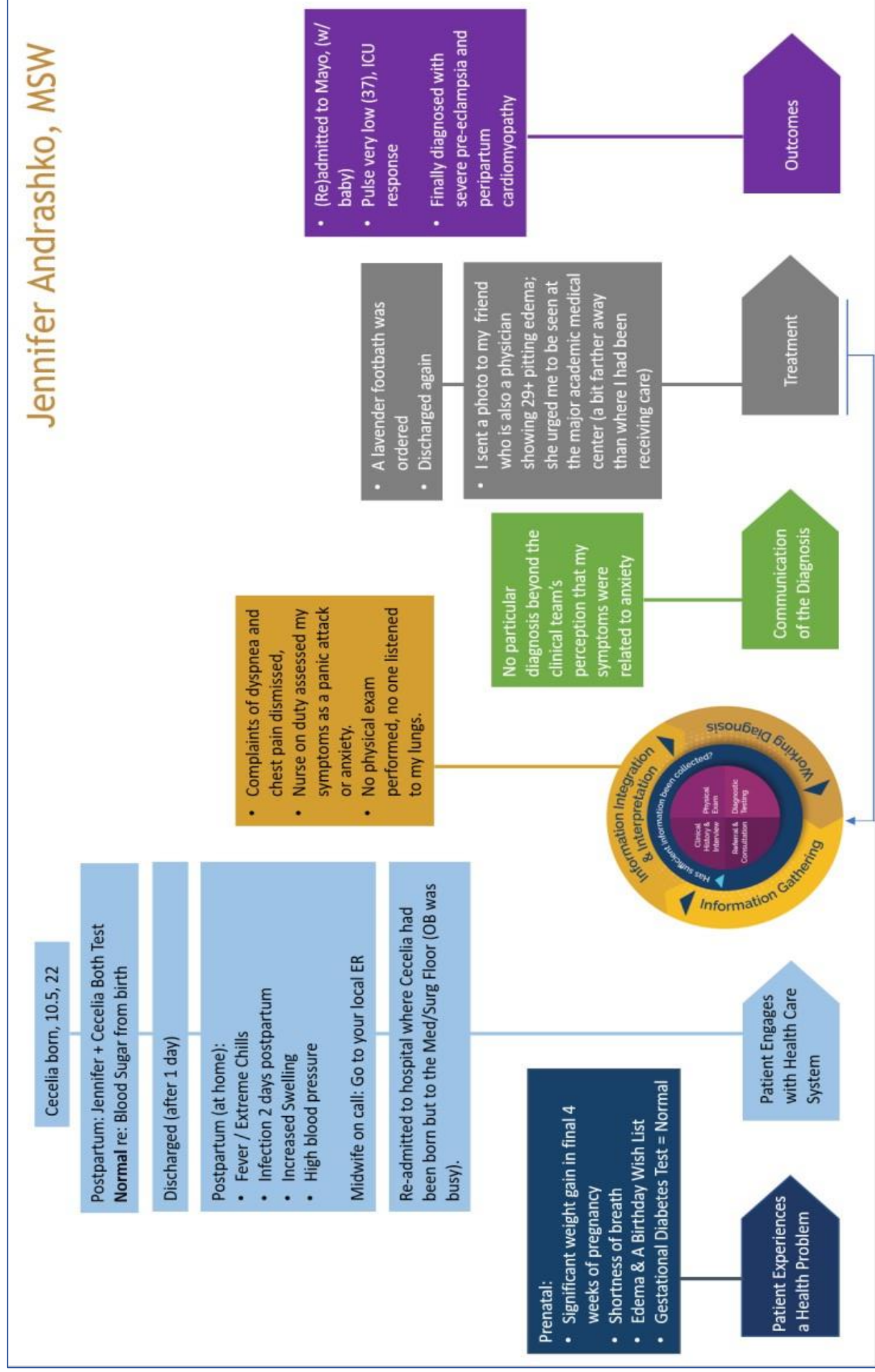
Jennifer Andrashko, MSW, is a social worker and social work professor at Minnesota State University in Mankato. She has a lifelong passion for community-building and service and cares deeply about health policy including improving equity and access to affordable healthcare and medication. As a mental health provider in rural Minnesota, she has been invited to testify in hearings at both the state and national level about the difficulty of accessing mental health care – especially for those living in small and rural communities. Jennifer is also an appointed member of the Minnesota Maternal Mortality Review Committee.

Jennifer’s diagnostic error began during the final weeks of her pregnancy, when she gained a significant amount of weight—so much so that she had to find an extra large pair of shoes because nothing else would fit over her swollen feet. She was discharged the day after delivery of her daughter, and when she began to exhibit signs of infection (chills, fever, and swelling), the midwife on call advised her to go to the ER. Jennifer’s complaints of significant shortness of breath were both dismissed and misinterpreted; the latter error caught by Jennifer in real time, as she realized she was being evaluated for a panic attack or anxiety, conditions she herself is trained to identify and treat. No diagnostic tests were ordered and no physical exam was performed; the only prescribed treatment was a lavender footbath and she was discharged with no diagnosis.

Upon returning home, her symptoms only worsened and when she measured the pitting edema in her lower legs and feet at 29 minutes (the scale for evaluating pitting edema ends at 3 minutes), a friend who is also a physician encouraged her to go, quickly, to the academic medical center near her. Upon admission, her pulse was found to be 37 and she was finally diagnosed with pre-eclampsia (that had been missed for several weeks prior) and severe peripartum cardiomyopathy. Jennifer was struck by the fact that this series of events could happen to her given that she has several of what are widely believed to be “protective” factors—being well-resourced, well-educated, and white. She stressed that, based on her experiences and those of her fellow patients, there are no factors that “protect” women or pregnancy-capable individuals from such harm; only factors—like being a person of a color—that further exacerbate the gaps and holes in the healthcare system. Given the devastating maternal mortality and morbidity statistics among communities of color, Jennifer feels compelled to fight for systems of care and equality that keep all women, pregnancy-capable individuals, and children safe.

Jennifer’s diagnostic story is mapped to the National Academies of Medicine Diagnostic Process Map on the following page.

Figure 1-5, Jennifer's story as outlined on the National Academies of Medicine Diagnostic Process Map





### *Clinical Experts Landscape Presentation*

Following the cases presented by the three patient speakers, a panel of clinicians provided their reactions to the powerful stories as well as context about the greater landscape of maternal health in the United States.



Bethany Sabol, MD, practices at the University of Minnesota, Department of Obstetrics, Gynecology, and Women's Health, is the Dept. Representative for the M Physicians Compliance and Risk Management Committee, and Chair of the Zero Birth Injury Committee for M Health Fairview. She completed her MD at the University of Illinois at Chicago in addition to a focused curriculum on urban medicine and health disparities.

Bethany was asked to comment from the OB/GYN perspective, where she sees the most common diagnostic breakdowns occur and where she thinks the biggest areas of opportunity are for improving maternal health. She offered that ideally things are captured as they develop

during the pregnancy—such as Jennifer's pre-eclampsia that had been missed for months before she delivered. Achieving optimal prenatal health is an important step, but as evidenced in the three expert patients' stories, even when there are no anomalies during the pregnancy, complications can still arise, and quickly. She stressed the importance of coordination and communication and endorsed much of what the expert patients had offered—having a person who can navigate and advocate for you, especially when you are not feeling well or are overwhelmed with the medical event that is unfolding.



Carl Berdahl, MD, is an Emergency Medicine Physician and Health Services Researcher at Cedars Sinai Medical Center and an Adjunct Physician Policy Researcher at RAND Corporation. After completing medical school and residency, he attended fellowship in the inaugural class of UCLA's National Clinician Scholars Program and obtained a Master of Science in Health Policy and Management from UCLA's Fielding School of Health, which included a concentration in Implementation and Improvement Science. His primary research objective is to improve the quality and safety of emergency care by designing better care processes and pathways.

Carl was asked to comment, from a system-level diagnostic quality perspective, what the system breakdowns are that lead to these types of diagnostic errors and where the biggest areas of opportunity are for system improvement to

address maternal health. Carl first remarked that a frequent breakdown in care provided in the ER setting is a lack of awareness by the medical team that a women or pregnancy-capable individual is pregnant or recently had a baby. He urged that finding ways to ensure this critical piece of information is immediately captured could contribute to better diagnostic and treatment outcomes. He further shared that ensuring immediate access to relevant information from specialists is important; the ER setting is by design equipped to manage and array of needs and conditions, and therefore a specific pregnancy or post-partum related issue requires may require specialized knowledge.



Denise Connor, MD, (she/her) is Professor of Clinical Medicine at UCSF and a founding member of the San Francisco VA Medical Center's Faculty Hospital Medicine Group. She attends on a range of inpatient services including the medicine ward service, a traditional teaching service, the Faculty Hospitalist Service, an attending-only service, the Co-Management Service, a consultative service for peri-operative patients, and the Swing Service, where she serves as Transfer Attending, Medicine Consult attending, and Procedure attending, while admitting patients and supporting the on-call team. She is the Director of the School of Medicine's Anti-Oppression Curriculum Initiative (AOCI). Through this role she collaborates with faculty, students, staff, and

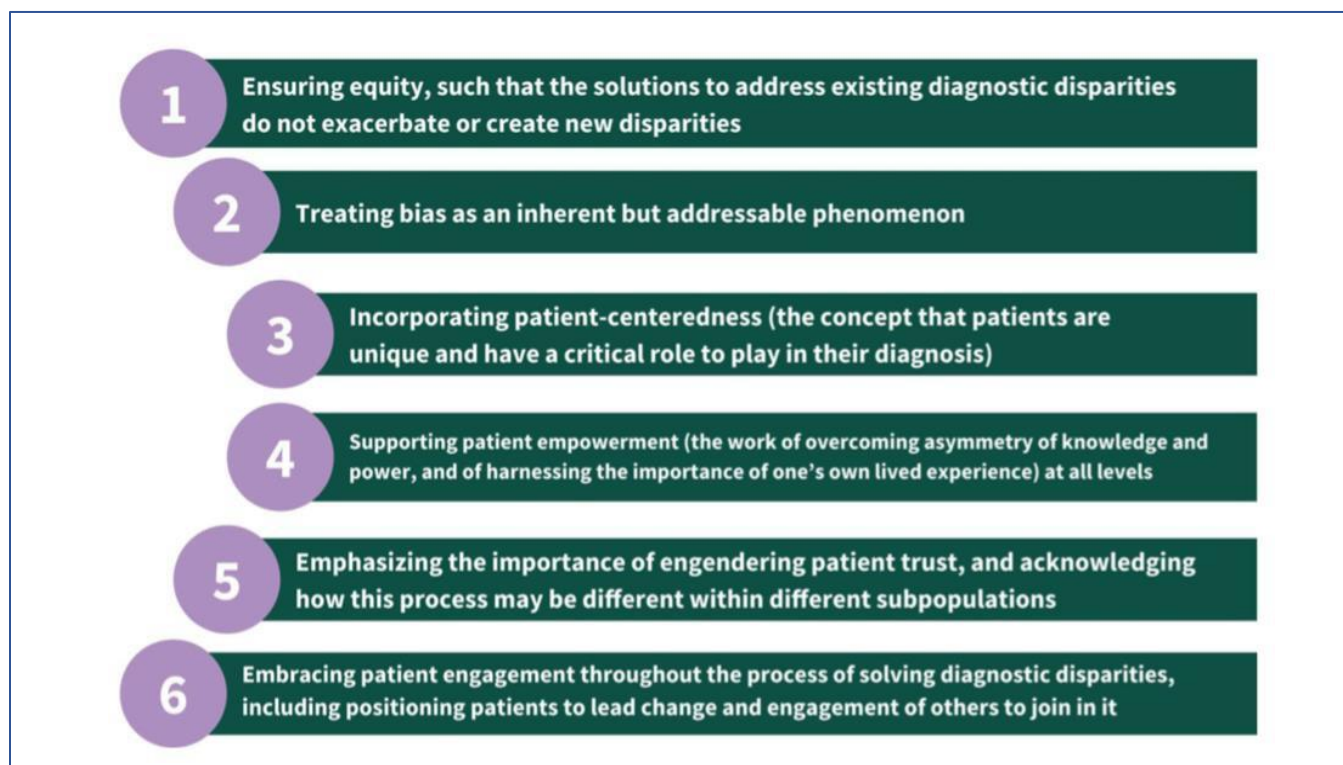
community members to elevate the School of Medicine's emphasis on justice, equity, anti-racism and anti-oppression across the entire four-year curriculum.

Denise was not able to join us in person at the Patient Summit, but she put together a video in which she was asked to explore the primary health equity issues that contribute to these diagnostic breakdowns and where the field should look for solutions. In her discussion, she surfaced much of the recent focus on health equity, but cautioned that the issues of disparities and unjust care elevated during the pandemic are not new. Rather, they are simply coming to light for more people. Denise provided key insight about the process of clinical reasoning, and the role that historical biases, racism, and systemic discrimination play in how clinicians (and others) form and keep mental models. She urged Patient Summit participants to keep in mind that a given clinician working up a given diagnostic scenario with a patient is not operating in a vacuum, but is operating within their structural, social, cultural, and historical contexts. Furthermore, she encouraged participants to work to understand patients within their own contexts, and to consider how solutions for diagnostic quality must be adaptable and workable in a variety of settings and systems. Finally, Denise focused on the critical importance of accurate and complete patient history as a hallmark of diagnostic quality, meaning patient/provider communication is paramount to

"things are not getting worse, they are getting uncovered. we must hold each other tight and continue to pull back the veil."  
Quote by adrienne maree brown  
shared during Denise Connor's  
remarks

achieving diagnostic safety. She framed the support of effective communication before and after the clinical visit as an area of exploration and concluded with citing an output of the joint SIDM and Johns Hopkins Disparities in Diagnosis project, principles for developing and prioritizing solutions in health equity, as shown in Figure 1-6 below.

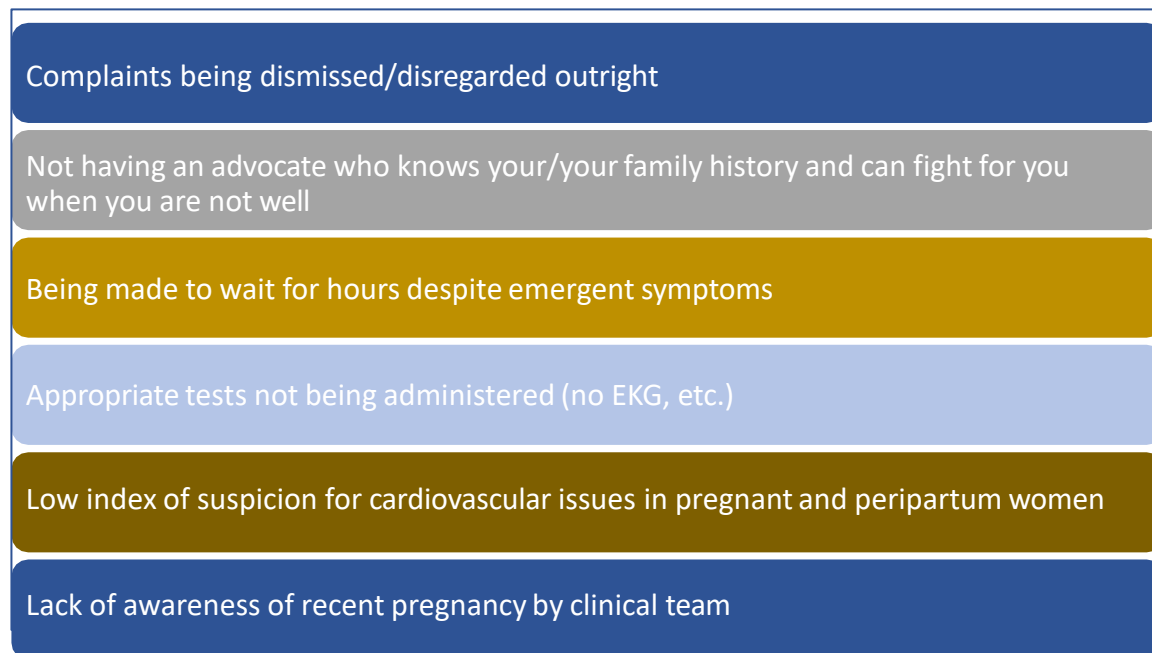
Figure 1-6, Six Principles for Developing and Prioritizing Solutions Unique to Diagnostic Disparities, *Exploring and Addressing Disparities in Diagnosis*, Johns Hopkins University and Society to Improve Diagnosis in Medicine, July 2021



### *Instructions and Transition*

In the final portion of the opening session, the participants were reminded of the instructions for breakouts and reminded of the focus for the three breakout rooms and their charge for the day. Among the many lessons and learnings from the incredibly powerful and rich stories presented by the patient advocates, and insights shared by the clinical experts, several key themes emerged for participants to carry with them to the workshopping segment of the day as detailed in Figure 1-7 on the following page. The charge for each group was not specific to any of these points however, and instead was framed as “what is a solution that may have prevented (in whole or in part) what happened to these women”?

Figure 1-7, Key Takeaways from Opening Session



The three breakout rooms were again described and participants asked to select a room to join. The three breakout rooms were:

- Patient-facing solution: Create a solution that would be used by patients or is patient-facing, such as a toolkit for use by patients, or a process for use during the patient intake process.
- Clinician-facing solution: Create a solution that would be used by clinicians or is clinician-facing, such as clinical training or a checklist for use by clinicians.
- System-level solution: Create a solution that is meant to be implemented at or is focused on the system-level.

It was stressed that we did not want participants to self-select to the room that was focused on their stakeholder type (i.e., patients should not automatically participate in the patient-facing solutions room). Instead, the value of the exercise—and in fact, the goal of the Summit—was to showcase the immense value in co-creating solutions with diverse stakeholders. To ensure that we had a roughly equal distribution of stakeholder type and number, we asked participants to take an informal vote to indicate which room they planned to join, and serendipitously, the group naturally divided roughly into thirds, and with a variety of stakeholder types in each room.



# PATIENT SUMMIT CONFERENCE PROCEEDINGS

PATIENT-FACING SOLUTIONS BREAKOUT ROOM



## PROCEEDINGS: PATIENT-FACING SOLUTIONS BREAKOUT ROOM

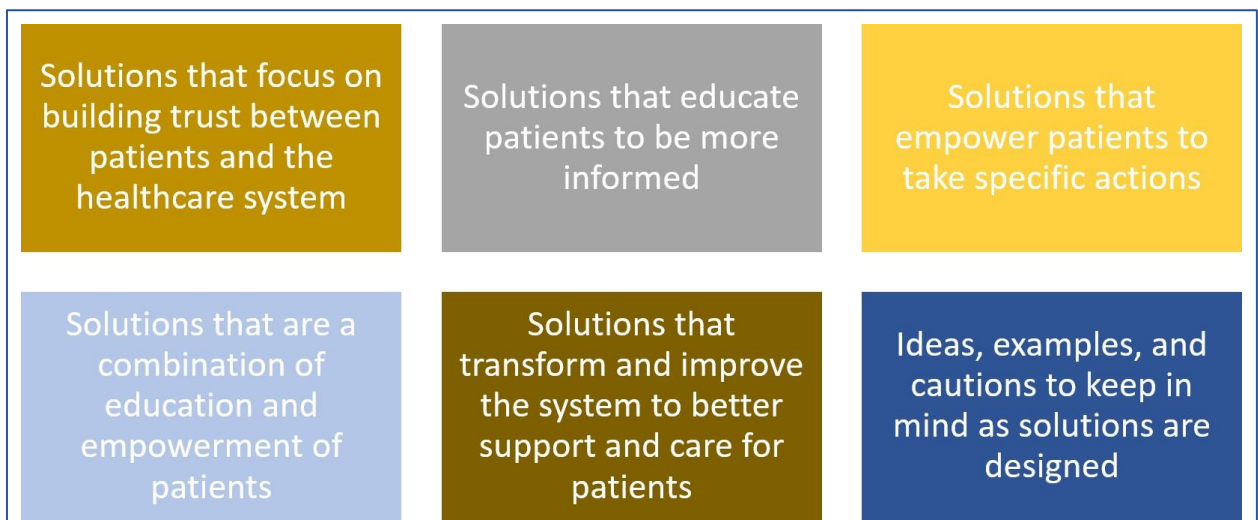
In the Patient-Facing Solution breakout room, the lead facilitator was SIDM Senior Patient Engagement Advisor Suz Schrandt, supported by SIDM Patient Engagement Committee member Gwen Mayes. Our expert patient discussant was Jennifer Andrashko, our expert clinician discussant was Sarah E. Slone, PhD, Doctor of Nursing Practice and APRN at Johns Hopkins, and our diagnostic quality expert discussant was David Kudlowitz, MD, Internal Medicine and Adult Hospital Medicine at NYU Langone.

The group began by doing a brief round of introductions, revealing a diverse collection of patients, clinicians, researchers, and others, from around the country—and the world. The charge for the group was provided one more time, and the first of the activities—a 90-second individual brainstorm—was described. Each participant was provided with a worksheet and invited to spend 90 seconds doing an individual “rapid ideation” brainstorm, with a focus on just getting ideas from mind to paper, regardless of how fully-formed.

“After waiting for hours, I finally had to leave—I had a days-old newborn at home who I needed to feed.”  
--Charity Watkins, describing her first ER visit that ended with no diagnosis

Next, the group engaged in a round-robin brainstorm, with each person offering one idea at a time, while the room facilitators captured the ideas (onscreen in the front of the room) and began to group them according to content and similarity. The contributions from the group covered a great deal of territory, including some suggestions or thoughts that were conceptual or framing more than pure ideas for solutions, but all were incredibly valuable. The ideas and conversation naturally organized into six primary categories of content as outlined in Figure 1-8 below. The full collection of generated ideas can be found in the appendix.

Figure 1-8, Outputs from Patient-Facing Solutions Breakout



Three key tensions—and that term is used in a positive connotation—emerged during the brainstorming and dialogue. Each were tremendously important and serve as proof points for the value of multi-stakeholder problem-solving, particularly the inclusion of patients as team members.

First, is the tension between the need to provide education and empowerment to patients in the absence of an existing patient-healthcare system relationship. A patient advocate and clinical social worker in the session vocalized this need, drawing particular attention to the dis- and mis-trust among communities of color, because of the shameful history of racism and mistreatment of minority patients in the healthcare system. It was articulated that before education and empowerment can happen and be effective, trust must be established, along with a sense of recognition and connection. These types of relationships could be formed by hosting community events, in which clinicians and researchers come to the patients—where they live, work, play, and pray— to get to know each other and understand each other’s cultures.

The second tension surfaced during the dialogue and through to the identification and formulation of the “single” solution idea, was the need to be mindful of and prevent overdue burden on patients and families, when we endeavor to provide education and facilitate empowerment. Everyone recognized that in an ideal scenario, a patient is informed about their conditions and feels equipped and empowered to ask questions and seek high-quality care.

“Back in the day, doctors used to come to you—do house calls. We don’t have that kind of connection now. We need to build that trust between the patient and clinical communities before many of these solutions can work.”

--Patient advocate and clinical social worker participant

The reality is often far from the ideal however, with patients too sick or weakened to effectively advocate, traumatized or shut down from being repeatedly dismissed or disbelieved by providers, or burdened by other life and societal factors that make navigating the complex healthcare system next to impossible. While many group members still advocated for patient education and empowerment, this desire came with the caveat of keeping the patient burden “in check”.

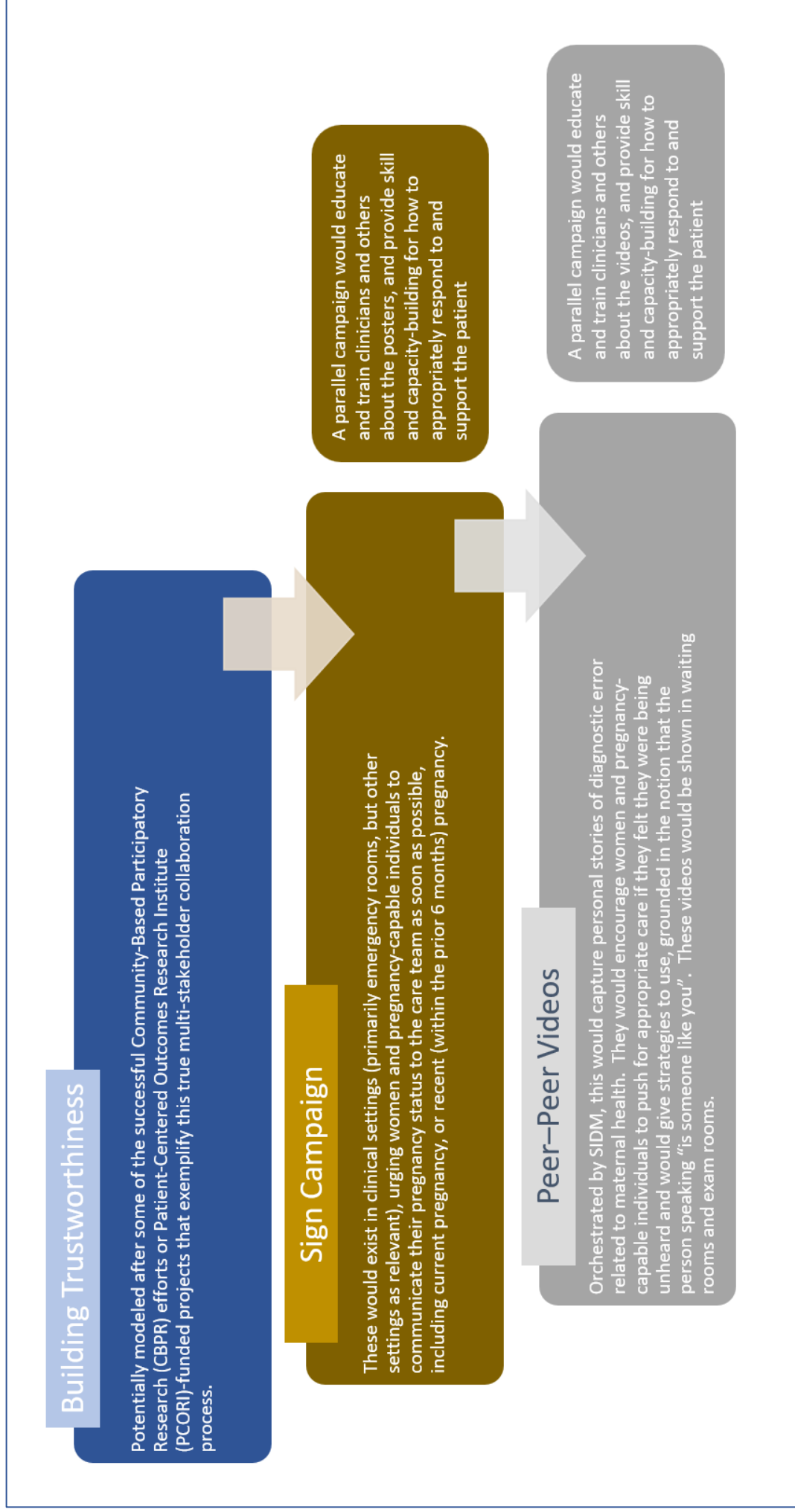
Finally, the third tension had to do with balancing the role of the patient with the role of the system that serves them. The analogy of a baseball pitcher and catcher was used, wherein no matter how skilled or talented a pitcher is, if the catcher is poorly trained or not equipped, even the best fast-ball cannot strike the batter out. Even if we equip patients from head to toe with everything they need to “go navigate” their health care, if the system shuts them down, be it through poor access, lack of patient/provider communication, failure to return test results, or other barriers, the patient cannot navigate their way out of a bad system. Again, many participants still wanted to seek solutions that empower and equip patients, but that workstream necessarily must be accompanied by an equal workstream in the opposite direction.

When it came time to vote, this breakout room opted for a simple up/down vote rather than using the multi-vote process because there was early and widespread agreement that some sort of patient-facing education and empowerment tool would be the most valuable, but with the powerful caveat that any such effort would need to be grounded in work to first establish trust between the patient and clinical community, and with the understanding that any such efforts need to be co-created with a diverse team that includes patients and community members.

Given time constraints, the group was not able to flesh out a great deal of detail for the final idea, but the general concept was to develop a suite of educational and empowerment tools for patients, beginning with two discrete efforts—a sign campaign and a peer-peer video series, all anchored in a trust and community building initiative. Additional details are laid out in Figure 1-9 on the following page.

As explained in the final section of these proceedings, the Summit Participants collectively agreed in the final session that the ideas generated in each of the three breakout rooms were worthwhile and given their interdependence, would be more effective if developed in concert with one another. Suggestions and ideas for next steps are in the final section of these proceedings.

Figure 1-9, Proposed Solution from the Patient-Facing Solutions Breakout





# PATIENT SUMMIT CONFERENCE PROCEEDINGS

CLINICIAN-FACING SOLUTIONS BREAKOUT ROOM

## PROCEEDINGS: CLINICIAN-FACING SOLUTIONS BREAKOUT ROOM

In the Clinician-Facing Solution breakout room, the lead facilitator was SIDM Director of Programs, Marie Jaffe, and PEC member Dan Berg. Our expert patient discussant was Wanda Tswago (of the opening panel), our expert clinician discussant was Bethany Sabol, MD (of the opening panel), and our diagnostic quality expert discussant was Kathy McDonald, PhD, Bloomberg Distinguished Professor of Medicine, Armstrong Center for Patient Safety and Quality, Johns Hopkins University.

The group began with introductions, and again, a diversity of stakeholder type and geographic location was represented. Due to time constraints, this group skipped the individual rapid ideation brainstorm and moved directly into the round robin brainstorming. Several key concepts emerged during the initial brainstorming including the need for clinicians to be exposed to experiential learning to better understand what it is like to “walk in the patients’ shoes”, and to be more appropriately suspicious for issues in the post- partum period.

Some of the concerns and issues raised in the opening session were echoed here, such as the need to ensure information about pregnancy status is surfaced very early in the emergency department setting. The emergency department setting in fact, was identified as the most probable location for solutions being generated, with the acknowledgment that pregnant women and pregnancy-capable individuals may see a variety of providers in ambulatory settings, but principles of innovation like feasibility and practicality, making it important to retain focus and be targeted.

The issue of urgency also came up frequently, whether through delayed consults or dismissed or ignored symptoms, and the group organized around the need to develop something that could serve as an alert, but with a sequence of required events to follow to prevent the alert from being ignored. Bias, across multiple dimensions, was also raised by several people and the hope and belief was that more standardized approaches for assessment and treatment of pregnant or post-partum women or pregnancy-capable individuals could be helpful by removing the potential for a given decision-maker to be swayed by implicit or explicit bias.

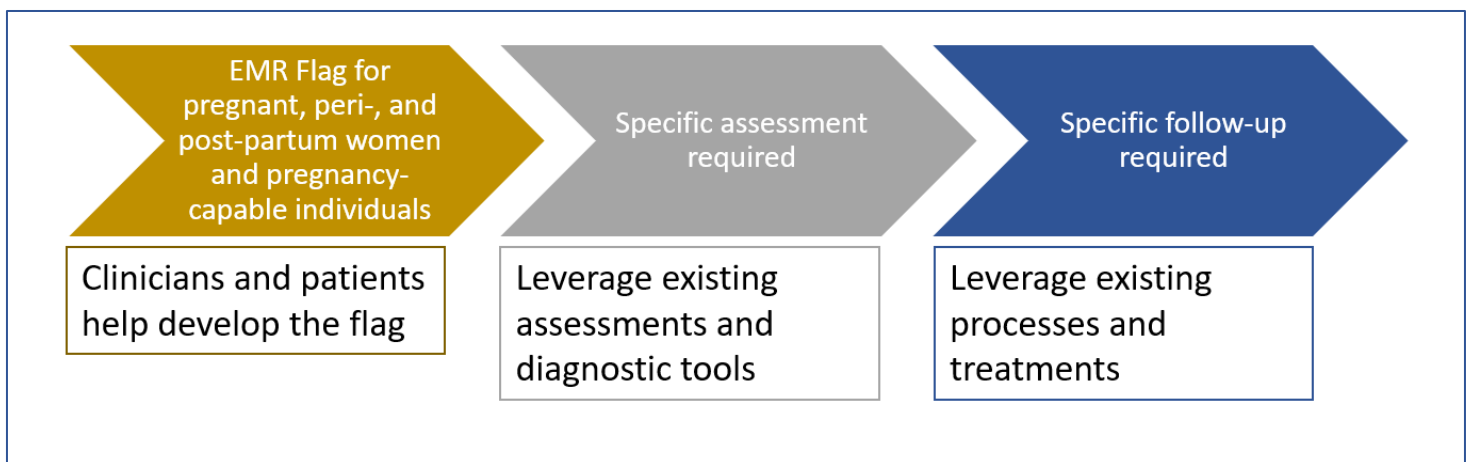
The discrete ideas generated in the discussion are provided in Figure 1-10 on the following page, organized into three general categories of “Tools”, “Training”, and “Processes”.

Figure 1-10, Clinician-Facing Solutions Breakout Room “Raw” Brainstorm Ideas

Tool	Training	Process
ED clinician checklist/Triage questions in ED	Simulation exercises/ “walk in patient shoes”	Develop process for flagging information in Electronic Medical Record
Hand off roadmap; who has the patient seen?	Primary care clinicians need to watch for anomalies, need retraining in schools for this	Improve and enhance communication from Reception and triage to providers
Discharge instructions circulated to other providers	Embrace curiosity in exam which leads to differential diagnoses	Process for prioritization of patient from moment of entry to ED
<a href="#">California Maternal Quality Care Collaborative</a> cardiovascular checklist	Be alert to bias: race, size, age, gender, and post-partum (blaming issues on depression)	Allow/enable more time to take history
Postpartum flag in Electronic Medical Record	Education and awareness of all providers on post-partum risks	Build feedback loops to ED and general practitioners to enhance learning and awareness

Ultimately, the group voted and galvanized around the concept of an Electronic Medical Record flag. It was acknowledged that this solution may more logically fit within the “systems-facing” solutions room, but as envisioned by the group, the flag was only the first in a series of steps, many if not all of which would be performed by clinicians. The ultimate proposed solution is described in Figure 1-11 below. Once again, because of time constraints the group was not able to develop a great deal of detail for the proposed solution, but suggestions and ideas for next steps are in the final section of these proceedings.

Figure 1-11, Clinician-Facing Solutions Breakout Room Proposed Solution







# PATIENT SUMMIT CONFERENCE PROCEEDINGS

SYSTEM-LEVEL SOLUTIONS BREAKOUT ROOM

## PROCEEDINGS: SYSTEMS-LEVEL SOLUTIONS BREAKOUT ROOM

In the Systems-Level Solution breakout room, the lead facilitator was PEC member Helene Epstein, supported by SIDM Director of Quality Improvement Gerry Castro, PhD, and PEC member David Meyers, MD. Our expert patient discussant was Charity Watkins, PhD (of the opening panel), our expert clinician discussant was Leah Burt, PhD, APRN, ANP-BC, Clinical Assistant Professor, University of Illinois Chicago, and our diagnostic quality expert discussant was Carl Berdahl, MD (of the opening session).

The group began by doing a brief round of introductions and then jumped into round robin idea generation, capturing all of the ideas on the screen in the front of the room. The full suite of ideas presented in Figures 1-12 and 1-13 on the following pages show the progression from the first round of brainstorm and discussion, to a narrowed-down and more targeted set of idea generation and discussion. Several key elements emerged throughout the discussion, such as the need to focus solutions on the ED setting, where all three of the expert patients presented and were ultimately diagnosed with their conditions. The need for post-partum support was also a critical factor, with one participant mentioning the field of postpartum doulas as an example of integrated patient navigation and support. The primary concern was the lack of knowledge and experience of the range of serious medical issues that could occur for pregnant and post-partum women or pregnancy-capable individuals among ED doctors and nurses.

The difficulty of “scope”, which also occurred in the other two rooms, was present here and relates to one of the most important outcomes of the Summit: that solutions cannot succeed if created and implemented in isolation. Throughout the discussion, needs were surfaced that were perhaps more suited for the rooms tackling clinician-facing and patient-facing ideas, but system-level solutions naturally revolve around the patients experiencing harm, and the clinicians working to make a diagnosis and begin treatment. As outlined in the final section, this necessary connection between patient, clinician, and system, resulted in a plan to combine the proposed solutions into a multi-factorial approach.

Figure 1 – 12, Systems-Level Solutions Breakout Room Idea Generation, Round One

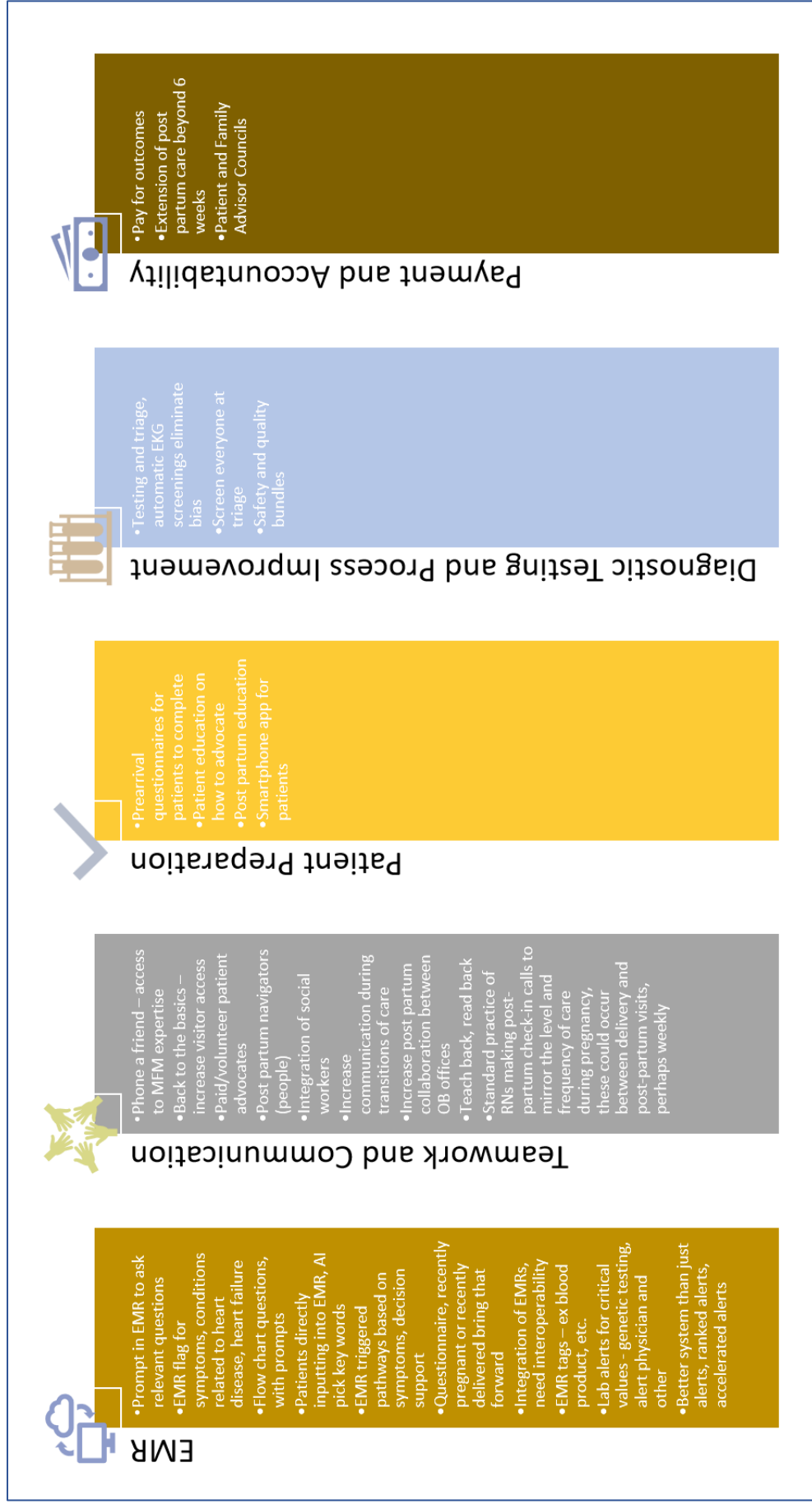


Figure 1 - 13, Systems-Level Solutions Breakout Room Idea Generation, Round Two

EMR	Teamwork & Communication	Extension of Post-partum Care Beyond Six Weeks
<p>Decision Support &amp; Algorithms</p> <p>A. Prompt everyone through EMR to ask question</p> <p>B. EMR data symptoms, conditions related to heart disease, heart failure to pop</p> <p>C. Flow chart questions, with prompts</p> <p>D. EMR triggered pathways based on symptoms, decision support</p> <p>E. Questionnaire, recently pregnant or recently delivered bring that forward</p> <p>F. EMR tag for pregnancy status</p> <p>G. Lab alerts for critical values - genetic testing, alerted physician, and other</p> <p>H. Better system than just alerts, ranked alerts, accelerated alerts</p>	<p>Phone a friend – access to MFM expertise</p> <p>1. For clinicians to call a high-risk ob specialist</p> <p>2. For patients to access specialist, doula, etc. for extended period of time</p>	<p>(additional details fleshed out in ultimate proposed solution)</p>
Patients directly inputting into EMR, AI pick key words	<p>Advocacy at the bedside</p> <p>1. Back to the basics – visitor access</p> <p>2. Paid/volunteer patient advocates</p>	
Integration of EMRs INTEROPERABILITY!	Integration of robust multidisciplinary support including social workers and RNs	
	<p>Enhancing handoffs &amp; transitions of care</p> <p>1. Post partum navigators (people)</p> <p>2. Increase communication during transitions of care</p> <p>3. Increase post partum collaboration between OB offices</p>	
	Teach back, read back	

The ultimate solution includes two key components as described here and in Figure 1 – 14 below.

- Current ED practice is to ascertain if a patient is currently pregnant or might be. Post-partum status is not commonly requested. Also, few — if any — ED settings include a maternal medicine expert on staff to review a pregnant or post-partum patient's symptoms to determine if their symptoms may be related and if they are indicative of a serious issue. The solution is to require all EDs to have access to a maternal medicine expert for a series of specific consultations and supports which would be expressly covered and part of the standard of care for women or pregnancy-capable individuals experiencing such complications. For example, these experts can automatically review every pregnant and post-partum patient's history and charts to recommend additional tests or screenings to avoid significant patient harm. They may be remote or in-person. They may include OB/GYNs, midwives, obstetric nurses, nurse practitioners, social workers with relevant experience, and/or doulas. The question of maternal status must be asked and one of these advisors consulted if the answer is affirmative.
- In order for this policy to work, the solution is to have major healthcare organizations set the post-partum period to two years. The current Medicaid and health insurance definition of post-partum is six months. That has been proven to be insufficiently short and likely contributes to significant breakdowns in diagnostic and treatment quality for women and pregnancy-capable individuals with peri and postpartum complications well after the current pregnancy coverage policy ends. The strategic question is who to approach first among those entities with a role to play, such as the Centers for Medicare and Medicaid Services, the American College of Obstetricians and Gynecologists, The Joint Commission, or large insurance companies.

Figure 1 - 14, Systems-Level Solutions Breakout Room Proposed Solution





# PATIENT SUMMIT CONFERENCE PROCEEDINGS

CLOSING SESSION AND NEXT STEPS

## CLOSING SESSION, VOTING ON THE “WINNING” SOLUTION

In the final portion of the Summit, all participants reconvened in the main room for a report out on the nominated solution from each breakout room. Designated spokespeople for each breakout room described their proposed solution with enough detail to allow the room to vote on which solution idea should receive SIDM DxQI Seed Grant funding. The three proposed solutions, as articulated previously were:

- A suite of educational support tools and resources for patients/families, initiated through a community-driven, trust-building process, and commencing with an ED sign campaign and collection of peer-to-peer videos to encourage women and pregnancy-capable individuals and their families to speak up when they are concerned complications have occurred.
- An electronic medical record “flag” to alert clinicians of potential complications following pregnancy, and a series of required activities including consults from maternal and peri- and postpartum clinical experts.
- An updated coverage policy that defines postpartum as a two-year period of time following pregnancy and requires coverage for consults (in person or remotely) with a clinician who is an expert on potential maternal postpartum health issues for every postpartum patient within the two-year redefined period.

“One can’t find what one doesn’t know to look for.”

--patient advocate and healthcare journalist, noting the lack of awareness of pregnancy and post-partum complications

It was agreed across all participants that all three of the proposed solutions were essential, and most notable amidst the conversations and report-outs was the incredible similarity between the rooms. Despite being divided into rooms tasked to focus on three different focal points, each group surfaced the need for all stakeholder types to be involved in the creation and execution of the solution, and each group surfaced that

their identified solution would not and could not work in isolation. One of the Summit participants made a motion to suspend the vote, and instead task SIDM and those interested Summit participants to move forward with a concept that combines and integrates the three solutions into a single coordinated approach to (begin to) address maternal peri- and postpartum health. An integrated version of the three proposed solutions is outlined in Figure 1 - 15, along with an example of how the trio of integrated solutions could look in practice to best serve and care for someone experiencing complications following pregnancy in Figure 1 – 16 on the following pages.

Figure 1 - 15, Visual Depiction of How the Three Solution Ideas Relate and Connect to One Another

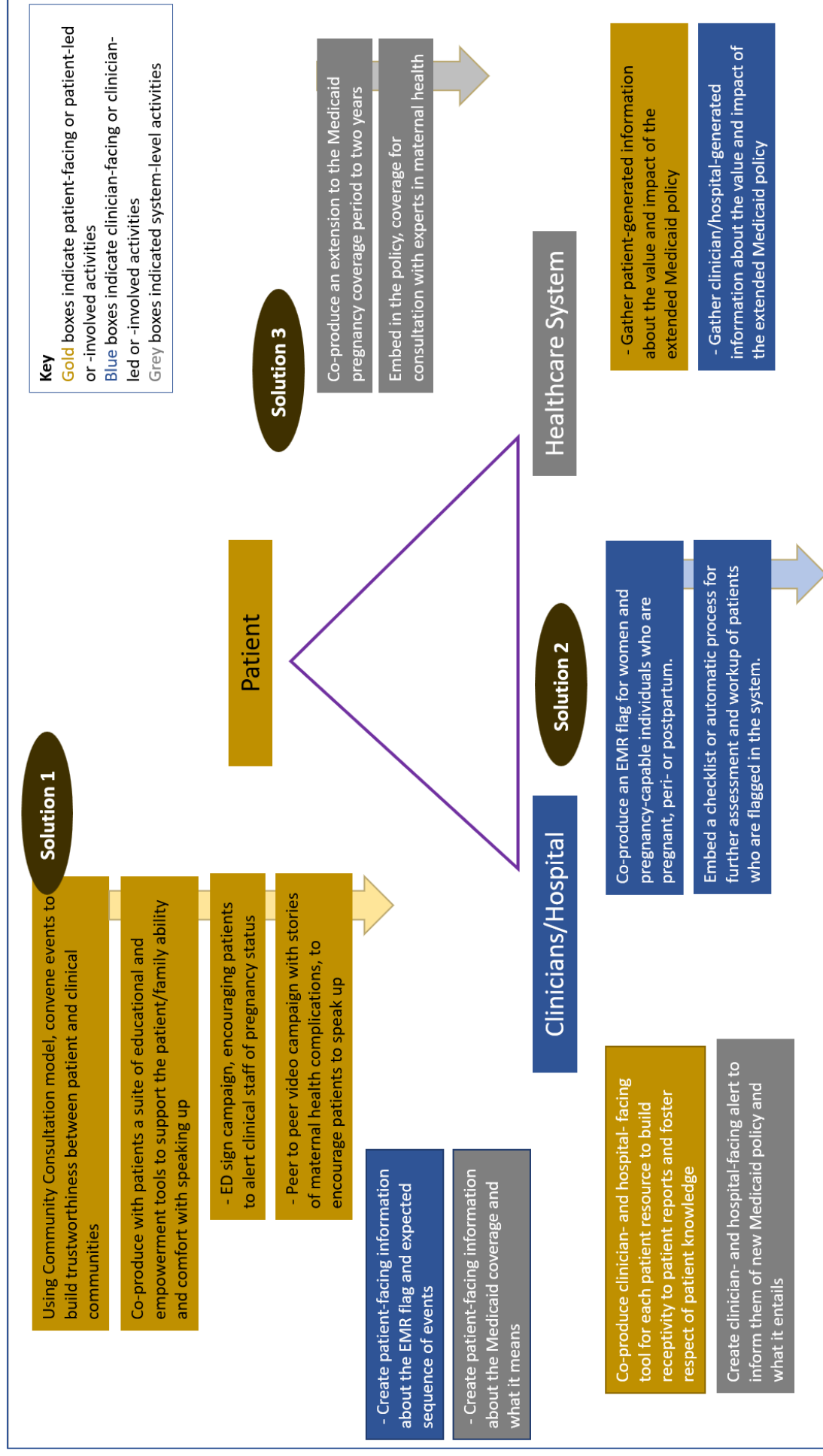
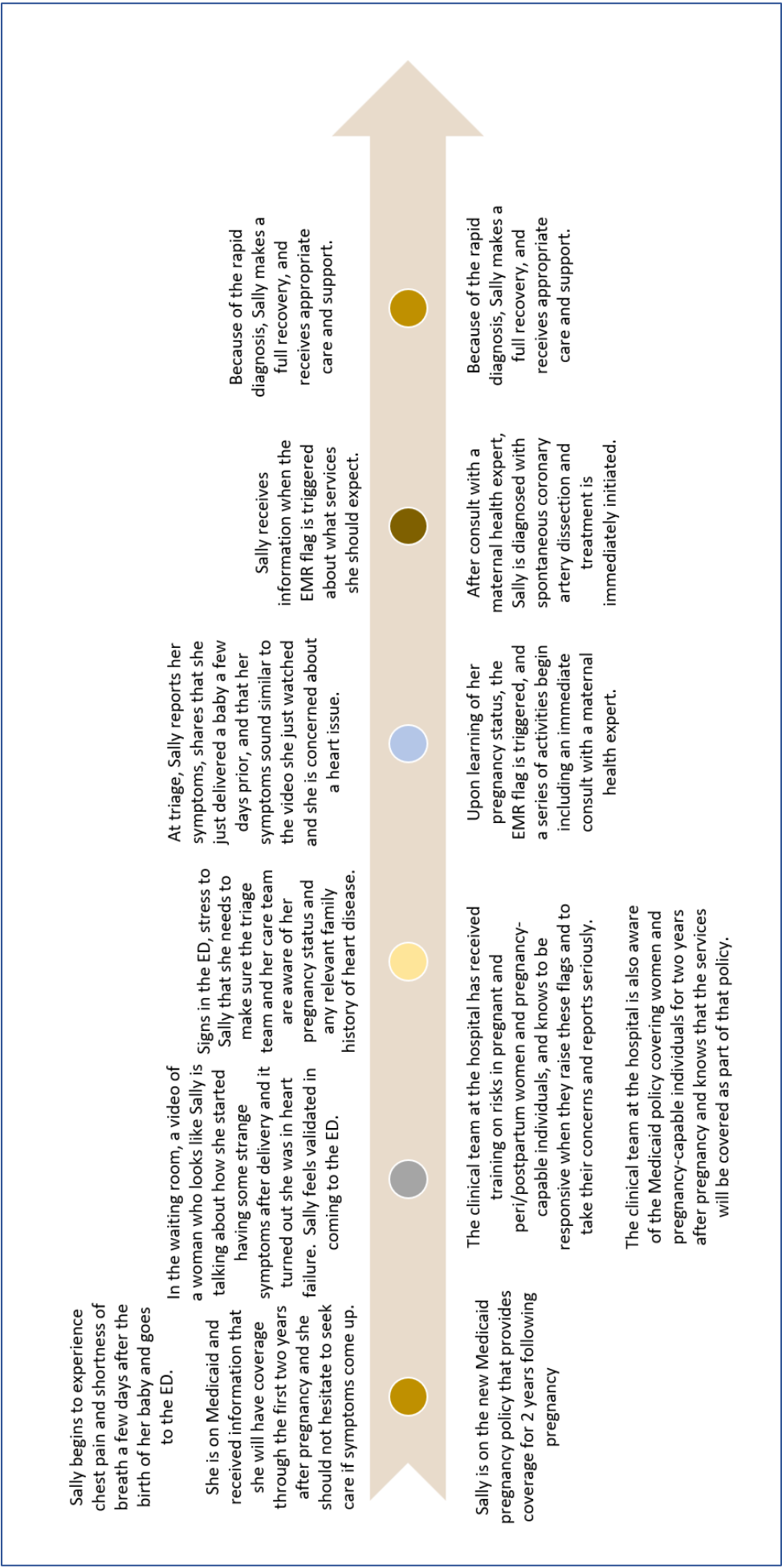




Figure 1 - 16, Example Scenario of the Three Integrated Solutions in Action



Beyond the specific proposed solutions, and the agreed-upon plan to coordinate and integrate them as a single initiative, the Summit yielded critical learnings and promising practices for future diagnostic quality innovation. Having a diversity of stakeholders in the room including different types of providers, individuals from different states and different countries, and those with different diagnostic quality areas of focus provides a rich environment for dialogue and creativity, with people learning from one another in real time, and ideas being co-created and formed through multiple iterations and revisions.

In particular, the role of patients, who have historically been excluded from such work—despite being those with the most to lose and the most to gain from the diagnostic process—was tremendously valuable. The expert patients who provided their lived experience as the orienting content around which the solutions generation was done, as well as other patients and patient advocates who participated in the Summit, grounded the work in the reality of the patient experience and corrected lines of thinking or discussion that were veering away from what is practical for or accessible to patients. The act of partnering with patients in any efforts to improve or create healthcare and research should be standard practice. In the field of diagnostic quality, patients and families touched by harm are particularly valuable as leaders and advisors, drawing from their unique vantage point during the trajectory of a diagnostic error to shape and inform preventions and solutions. By executing the Summit in this democratized way, SIDM sought to provide a roadmap for others aiming to partner with patients in similar innovation efforts.

## NEXT STEPS

Given the vision to integrate the three proposed solutions into a larger, multi-pronged initiative, funding beyond a SIDM DxQI Seed Grant will likely be necessary, and those interested in partnering with SIDM to support and foster this work are encouraged to reach out to SIDM to advance the effort. Central to the concept is that all stakeholder types are necessary as partners to develop each element of the proposed initiative, and each component of the initiative directly touches all other stakeholders. This output, even in its current nascent form, is a fitting and successful end to what was a dynamic and diverse event. The goal of the Summit, aside from the generation of important ideas, was to cement the critical importance of including patients alongside clinicians, researchers, and others in efforts to innovate. The patient participants in the Summit certainly brought that truth to bear, and the clinician, researcher, and other healthcare stakeholders involved further demonstrated the value and necessity of bringing a variety of perspectives and experiences together to achieve optimal creativity and viability.

For more information about how to be involved, contact Tim Browning at [tim.browning@improvediagnosis.org](mailto:tim.browning@improvediagnosis.org).

# PATIENT SUMMIT CONFERENCE PROCEEDINGS

APPENDICES

## Appendix A: Patient-Facing Solutions Breakout Room, “Raw” Brainstorm Ideas

Things to keep in mind about potential solutions	Fixing the system to support patients	Patient education	Patient empowerment
Look at patients before us; trends in patient care of related conditions; lessons learned from other countries	Give people permission to speak up	Education for patient regarding pertinent history with emphasis on family history (Something like the SIDM Patient toolkit—modified to be more accessible/usable)	Create a ‘buddy system’ because there is safety in numbers; post-COVID re-examine the access of family
Registry of stories – for commonalities – although individual patients have unique circumstances there are common aspects of every patients stories	Perceptive questions more specific to the individual patient; e.g., swelling ankles	3-part PSA “I’m pregnant” “I’m post-partum” “I’m breastfeeding”	Bring a patient to advocate for them; is this realistic for many patients, especially inner city hospitals? Have someone with you to help ‘listen’ to what is being said;
Do not put the responsibility on the patient	Communication skills; dismissive of patients concerns; language/words between patient and provider create a gap	Patient education (family member) of expectant mothers about risk of high risk pregnancies; e.g., heart disease	Advocate for yourself; learn to speak up; teach children to think beforehand to identify questions to ask
Don’t assume from the beginning that there is trust among the communities who access healthcare system (historically physicians would come to the family’s home, take more time). Come into communities to restore trust and get more information—community events, with faith homes, clinicians, building relationships and trust—health community is out there—going to where	Open communication “hearing the patient” – do not want them to “shut down”	Genetic testing if there is a family history; genetic counseling; what is the risk going forward	Polar Express: “are you sure?” – empower patients to ask a follow up question, “what haven’t you told me?”

## Appendix A: Patient-Facing Solutions Breakout Room, “Raw” Brainstorm Ideas, cont’d

Things to keep in mind about potential solutions	Fixing the system to support patients	Patient education	Patient empowerment
the patients are—this is the Community Consultation model			
A system that has easy access to patient’s medical history from birth to current day; it can happen (Native American health system)	Recognizing gender influences in additional racial biases, know or not in addition to “are you sure?”	Patient education during pre-natal care to include what happens after delivery; red flags to watch for	Ask “what else could it be?”
Collect information on where women/ pregnancy-capable individuals receive information so these organizations/entities are involved	Designated staff in the ER to talk, counsel, coach the patients while waiting to maximize their interaction with healthcare team; should they be medically trained? Maybe both; e.g., social worker, nurse aides	Patient-facing signs or supports in the clinical setting such as those alerting the importance of sharing/ reporting patient/family history	Patient stories—REAL stories, that empower patients/families to speak up when something feels wrong (institution agnostic)
Acknowledge tension between patient and system – who is responsible? Whatever is developed has a two-part solution both need to be involved in solution.....	Expand the ‘touchstone’ appointment (6 weeks) to include more long term input		Permission to ‘escalate’ an issue and ‘how’ to do it so that you receive the care you need, Let patients know if there is a “Rapid Response Team” and how to access it and use it when needed
Differences in chronic and acute access to care is underlying concern	Expand the ‘touchstone’ appointment (6 weeks) to include more long term input		Grow the network of post-partum women and pregnancy-capable individuals to advocate in the system;

## Appendix A: Patient-Facing Solutions Breakout Room, “Raw” Brainstorm Ideas, cont’d

Things to keep in mind about potential solutions	Fixing the system to support patients	Patient education	Patient empowerment
Partner with patients to build in patient ideas for future research; this should be ongoing to generate research ideas and designs	ICE, “Ideas” “Concerns” “Expectation” – could put tablets in waiting room to have patient write down before the time with doctor and staff; doctor can ask “what did you write on the paper before coming in)		Empower patients across the board to be confident in speaking up; asking questions of providers (especially women and pregnancy-capable individuals)
Childbirth is considered a ‘natural part of living’ and that influences perceptions and responses to concerns	More navigators especially if on your own		





## Brainstorming Worksheet



We're going to take about 90 seconds (don't worry, we'll set a timer!) to let everyone do some "rapid ideation". The idea is to just let your thoughts flow onto the paper without judgment or editing and see what you end up with. When the 90 seconds are done, you'll have an opportunity to share your ideas with the group.

The question for your brainstorm: Based on what you heard in the opening session, what ideas do you have for preventing the types of diagnostic errors the three patient advocates experienced? The types of solutions we are hoping to generate will be timely, feasible, ripe, patient-engaged, scalable and sustainable.

*Keep in mind, our room is focused on solutions that would be patient-focused or used by patients.*

\*worksheets were personalizd for each breakout room

## Building out the Solution Idea

Facilitator Questions	Group Responses
What is the location for the intervention?	
What is the specific problem the intervention aims to solve	
We need a clear description of the intervention and rationale for the intervention	
To what segment or segments of the Diagnostic Process would this intervention apply?	
What is the population to whom this intervention would apply?	

How would the intervention be created?	
How would the intervention be implemented?	
What are the barriers to success we can foresee and how might we address them?	
How would the intervention be evaluated for effectiveness? How would we know it is working?	
If effective, how would the intervention be scaled or expanded for greater uptake and use?	



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