Project PIVOT:

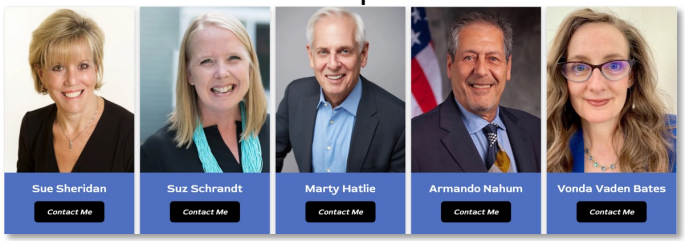
(Patients Involved in deVeloping Outcomes Together)

Improving patient safety, diagnostic excellence, and reducing biases in care by learning from **patient-reported experiences and outcomes** that matter most to patients, families, and communities

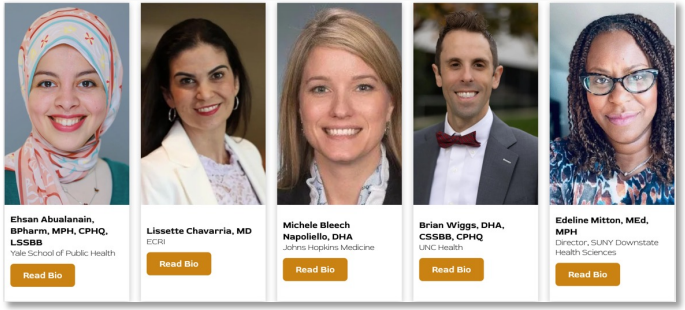
Project PIVOT was partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASCS-34604).

Project PIVOT Team

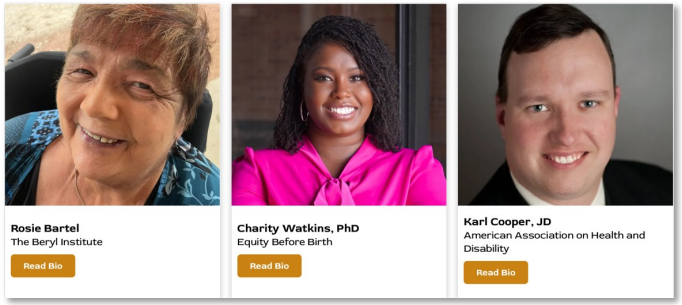
Leadership Team



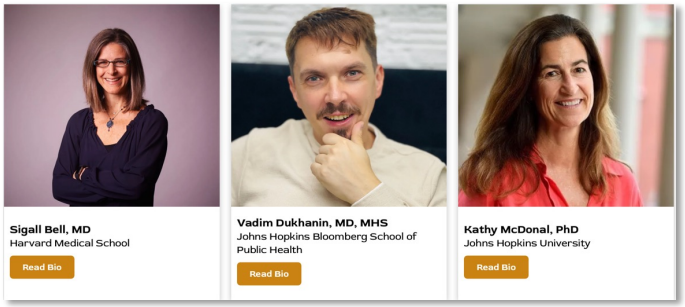
Data Analysis Team



Priority Population Team



Research Team



Healthcare System Leader

Divvy Upadhyay, MD, MPH
Geisinger Health

The Problem

Medical error is the 3rd leading cause of death in the United States.
Diagnostic errors harm approximately 800,000 Americans annually

Medical and diagnostic errors disproportionally impact the most vulnerable populations, in part, due to biases and misconceptions

Current measures to understand the problems are inadequate

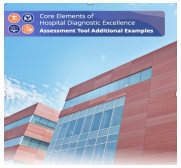
OIG reported in July 2025 that “Hospitals did not capture half of patient harm events, limiting the information needed to make care safer”

There is a national priority to **learn directly from patients and families** to improve patient experiences and outcomes related to patient safety, diagnosis, and discrimination/bias.

CMS' Patient Safety Structural Measure

Our hospital **incorporates patient and caregiver input about patient safety events** or issues (such as **patient submission of safety events, safety signals from patient complaints or other patient experience data, or patient reports of discrimination).**

CDC's Core Elements of DX Excellence In Hospitals



Our hospital includes questions that assess concerns about diagnosis in patient experience surveys.

The **Leapfrog Group's** Recognizing Excellence in DX

Senior administrative leaders take action to encourage both **patient and staff-reported diagnostic errors and concerns and put systems in place for safe and easy reporting.**

IHI's Safer DX Checklist

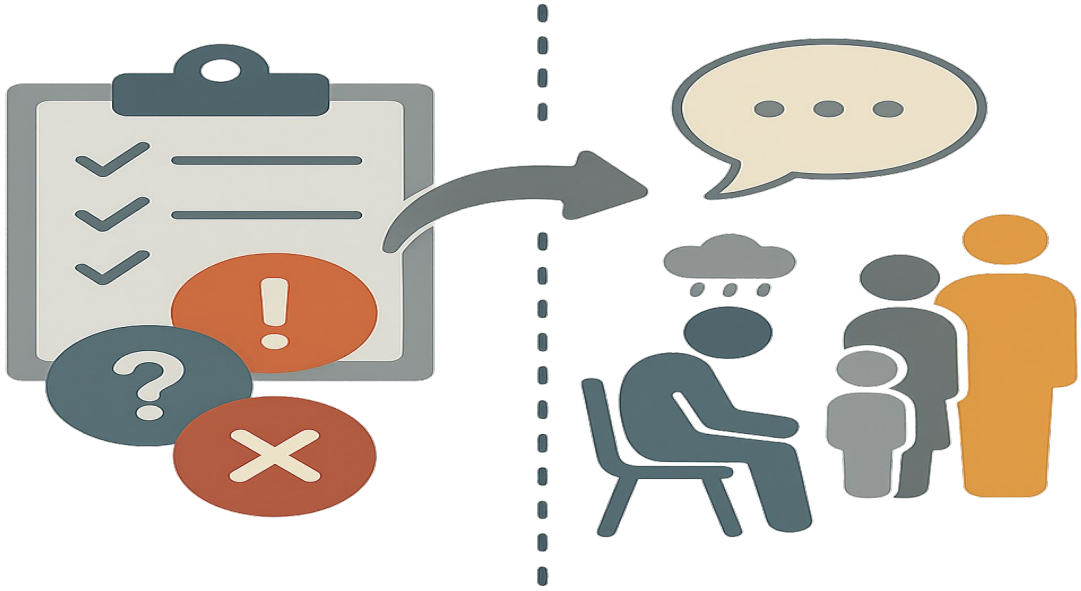
Health care organization actively **seeks patient and family feedback** to identify and understand diagnostic safety concerns .

Patient-Centered Outcomes Research Institute

PCORI research uses Patient Reported Outcomes (PROs) as a crucial data source to understand **what matters most to patients,** making the patient perspective central to its research.

BUT……

Most of the current tools/surveys used in research and quality assessment do not directly ask patients about their experiences and outcomes related to unsafe care, missed, wrong, or delayed diagnosis, or bias in their care…or how it impacts them and their families.



Long-Term Goal of Project PIVOT

Integrate new survey questionnaire items into national, organizational, and research quality measures (such as HCAHPS and PREM, and PROM surveys) that address patient safety, diagnostic accuracy and timeliness, and biases in care that have been identified and prioritized by patients

Key Principles Underlying Project PIVOT

Patient and Family-Centered and Lived-Experiences Led

Building Community, Partnerships & Inclusion with all Stakeholders

Focus on Vulnerable Populations

Creative Engagement Methods and Rigorous Qualitative Methodologies

What did Project PIVOT DO?

9

Engagement events (in person events, surveys, webinars, storytelling sessions, focus groups, conferences)

349

Participants:

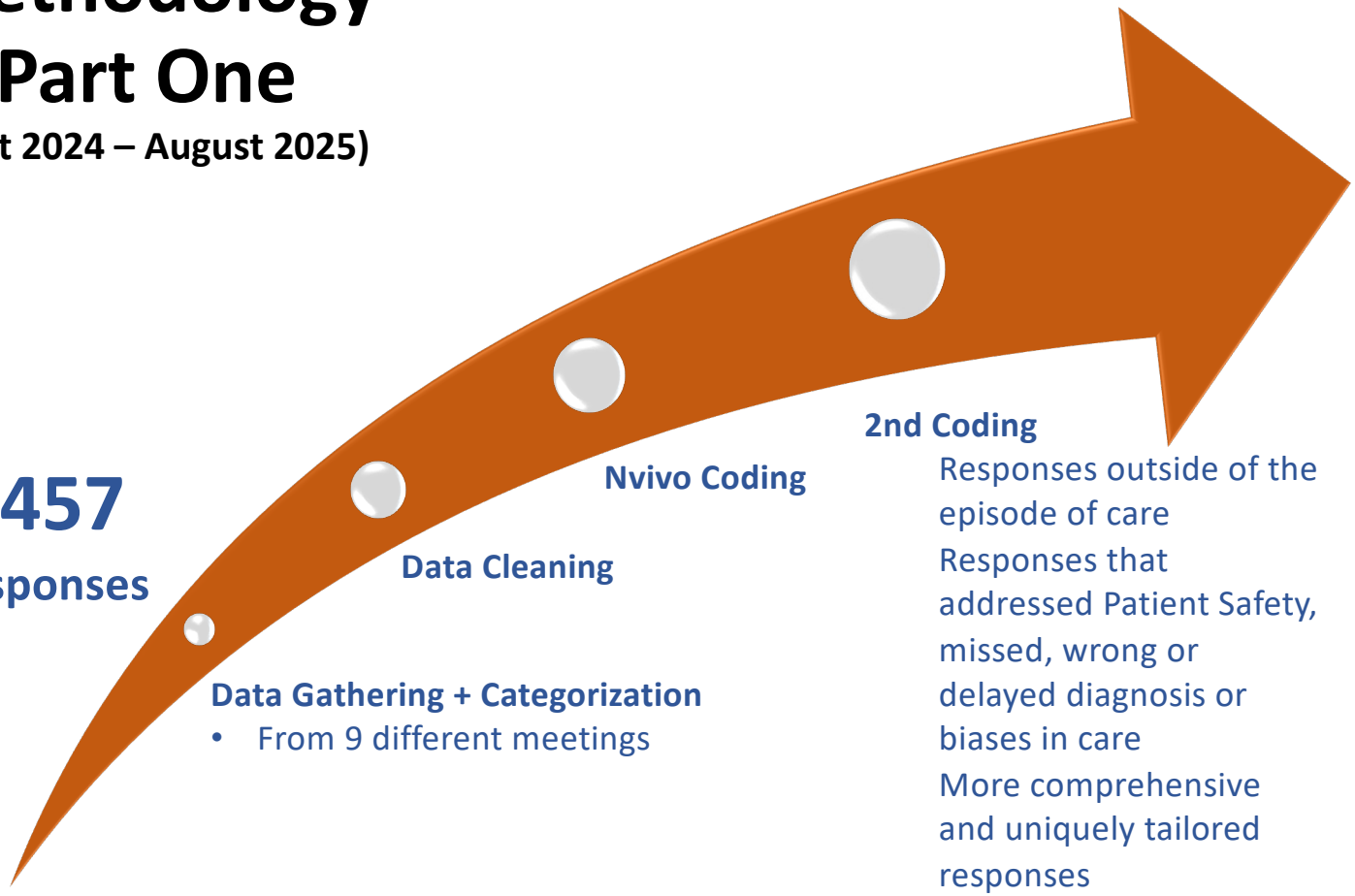
- 100 “patients”
- 149 professional stakeholders
- 100 unknown primary affiliation

2457

Individual responses

Methodology Part One

(Sept 2024 – August 2025)



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Responses

Data Gathering + Categorization

- From 9 different meetings

Data Cleaning

Nvivo Coding

2nd Coding

Responses outside of the episode of care

Responses that addressed Patient Safety, missed, wrong or delayed diagnosis or biases in care

More comprehensive and uniquely tailored responses

- Patient Safety (in general)
- Diagnostic Safety
- Discrimination and Bias
- Transparency
- Birthing People of Color
- Older Adults
- People with Disabilities

48 Themed Lists/Responses

86 Population-Specific Responses

Themes of the 48 Patient Prioritized Survey Questions (What do patients want to report?)

Harm: Physical, emotional, psychological, and financial harm to patients and families and how it impacted them	"What happened?"	Patient Safety Events	Being dismissed	Timeliness and accuracy of diagnosis, triage, and treatments
Bias in care	Real-time access to ALL and accurate medical records	Patient and family education and support. Having enough TIME	Patient and caregiver engagement in decision-making and discharge plans	Informed of mechanisms to escalate care or get a second opinion
Information in a language that is easily understood	Discharge Understandability, DX post-discharge, returning to ED	Coordination of care	Cultural and linguistic specific competencies	Accessibility and accommodations
Data breaches, data being sold, and safety during cyberattacks	How a harm event (or near miss) was managed by the healthcare system	If informed how to report harm events	Cover up of medical error	Perceptions of safety and trustworthiness

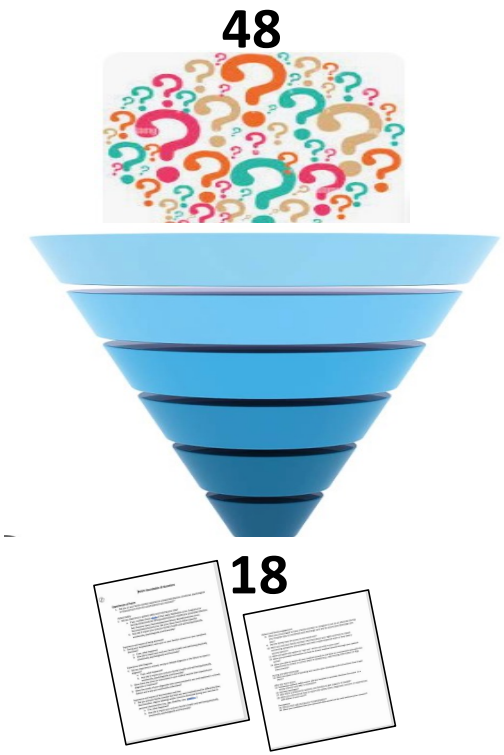
Which of the 48 PROs and PREs would be most "implementable" and connect the dots between what patients want to report and what our nation's leaders are calling for?

WHAT PATIENTS WANT TO REPORT

CONNECT THE DOTS

WHAT OUR NATION'S LEADERS ARE CALLING FOR

Mapped the 48 patient-generated questions to expectations and best practices identified in national patient safety and diagnostic safety initiatives



Feedback mechanism

Provide insights into the degree to which these national initiatives are being meaningfully implemented in practice.

CMS' Patient Safety Structural Measure

CDC's Core Elements of DX Excellence In Hospitals

National Action Plan for Patient Safety

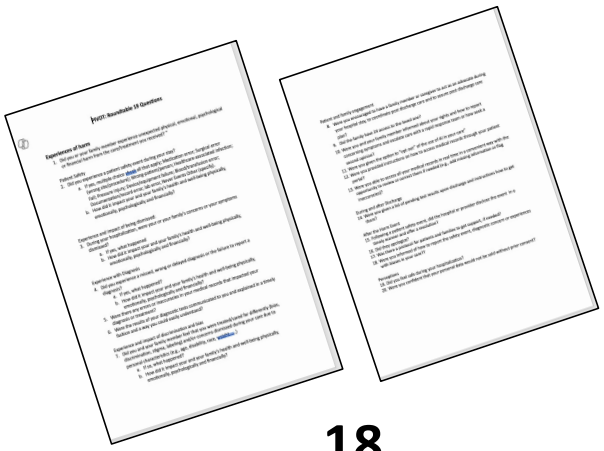
The **Leapfrog Group's** Recognizing Excellence in DX

ECRI's Top 10 Patient Safety Concerns 2025

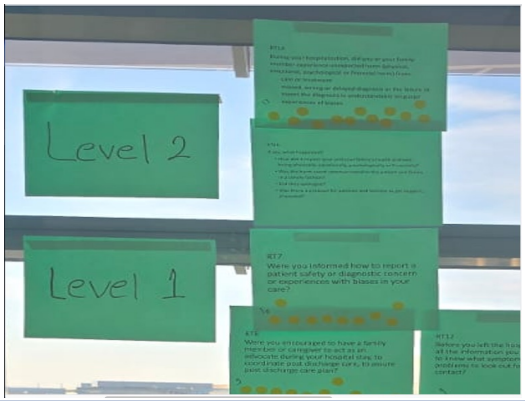
IHI's Safer DX Checklist

AHRQ's National Action Alliance

Using the 18 questions, we used a modified threshold upvoting with point allocation voting for separate groups of patients and stakeholders



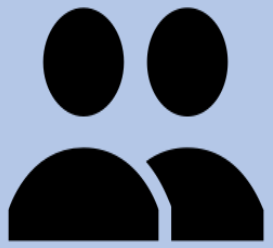
18



Patients & Families

Health Professionals

Shared Priorities



- Harm from Care, impact and response
- Reporting Safety, DX and bias in care concerns
- Being Dismissed
- Family Member or Caregiver as an advocate
- Bias in care
- Understandable medical record Information
- Discharge information re: symptoms and who to contact
- Test results in a timely and understandable manner
- Escalation of care/seeking a second opinion

UNIQUE TO PATIENTS/FAMILIES

- **Pending test results at discharge**

UNIQUE TO HEALTH PROFESSIONALS

- **Perception of safety**
- **Medical record accuracy and the means to correct them**

#1 survey question for both patients and stakeholders

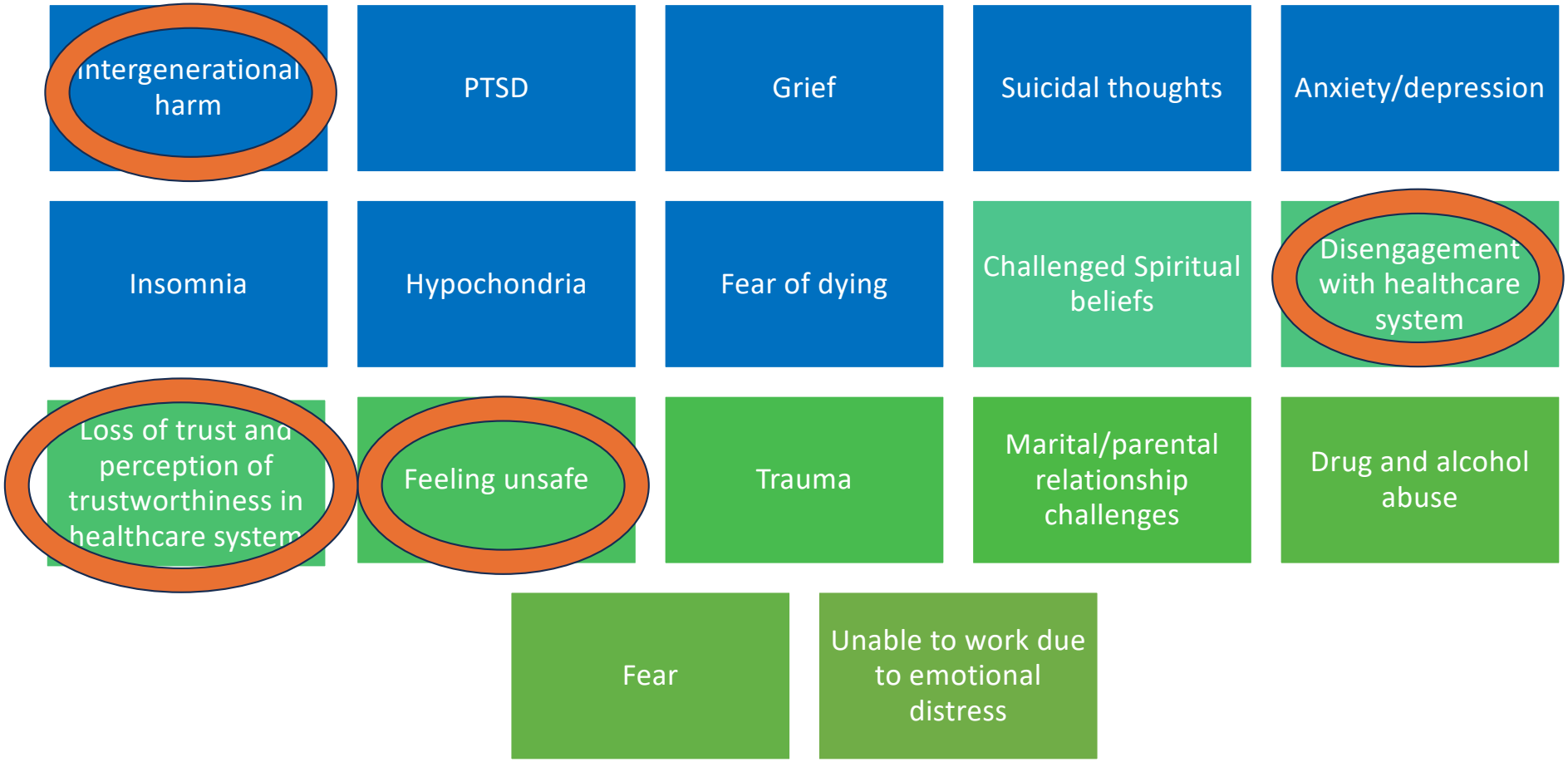
Did you (or a family member) experience unexpected harm

from the care/treatment you received? *If so, what happened? How did it impact you and your family? How was the incident managed?*

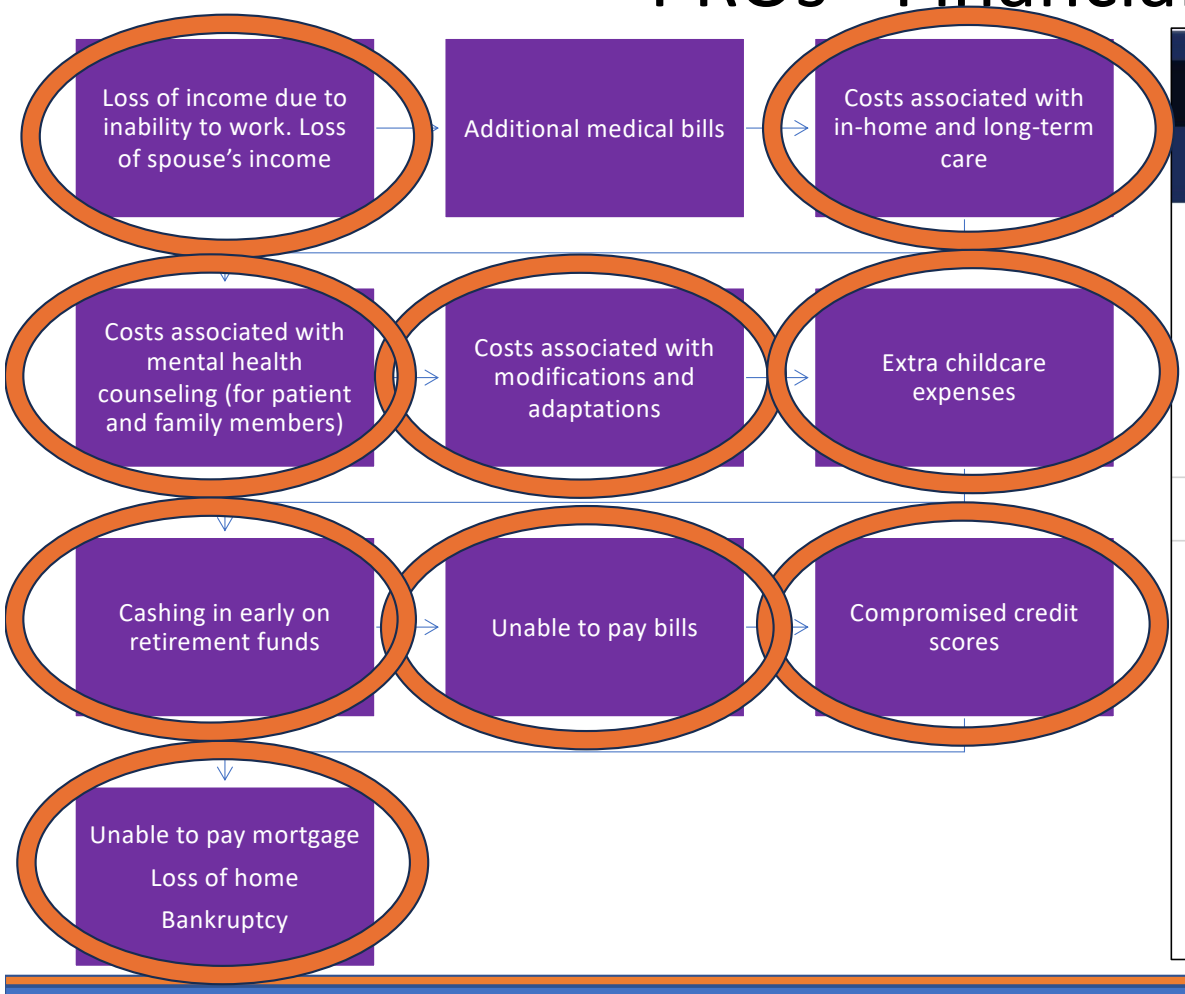
Patient Reported Outcomes (PROs) - Physical Harm

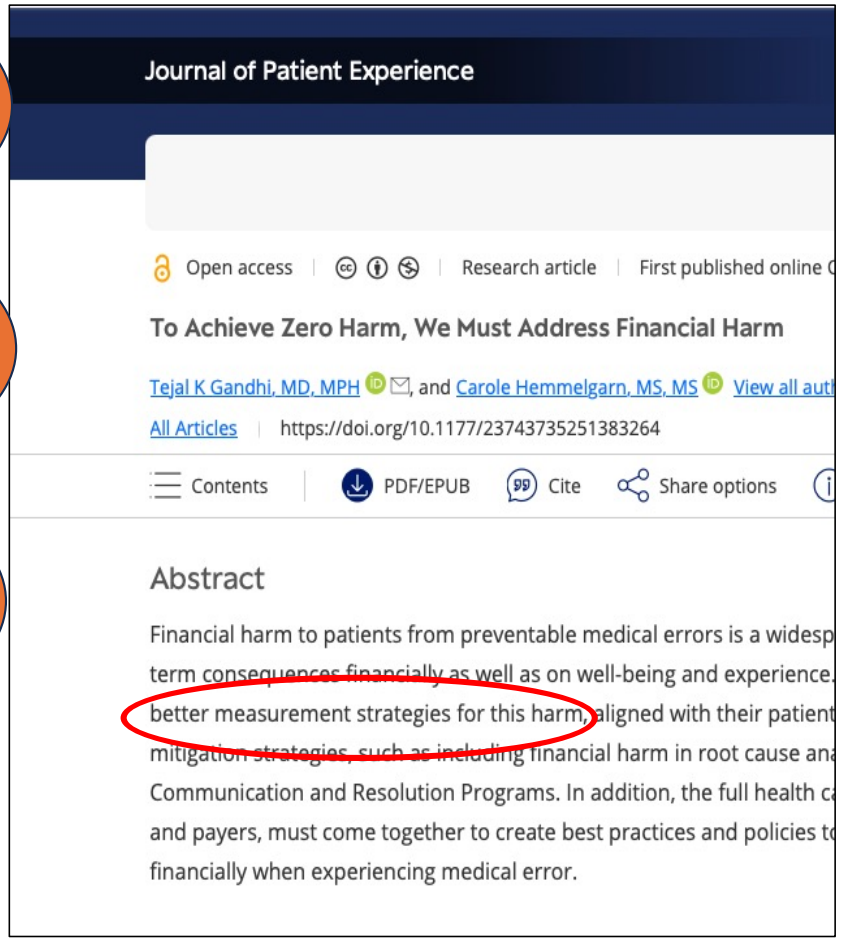
Death	Long term disability Amputations	Days alive were shortened – didn't get to say a proper goodbye	Pain	Diminished quality of life	Unable to do normal daily activities Loss of lifestyle
Near death	Complications with future pregnancies Inability to carry another child	Lost days of school or work	Unnecessary treatments	Lifetime medical challenges	Unable to work due to physical impacts
Longer recovery time	Time away from family	Readmission to hospital or ED after discharge	Heart failure	Worsened conditions and symptoms	Emergency surgery
		Years lost from living a healthy productive life	Stress induced migraines , hives or other physical manifestations of stress		

PROs - Psychological and Emotional Harm



PROs - Financial Harm





Journal of Patient Experience

Open access | Research article | First published online

To Achieve Zero Harm, We Must Address Financial Harm

Tejal K Gandhi, MD, MPH, and Carole Hemmelgarn, MS, MS View all auth

All Articles | https://doi.org/10.1177/23743735251383264

Contents | PDF/EPUB | Cite | Share options

Abstract

Financial harm to patients from preventable medical errors is a widesp
term consequences financially as well as on well-being and experience.
better measurement strategies for this harm, aligned with their patient
mitigation strategies, such as including financial harm in root cause ana
Communication and Resolution Programs. In addition, the full health c
and payers, must come together to create best practices and policies t
financially when experiencing medical error.

Shared Priorities

- *Were you informed how to report a patient safety or diagnostic concern or experiences with biases in your care?*
- *During your hospitalization, were your or your family members' concerns dismissed?*
- *Were you encouraged to have a family member or caregiver to act as an advocate during your hospital stay, to coordinate the post-discharge plan and care?*
- *During your hospitalization, did you or your family member feel that you were treated differently due to personal characteristics?*
- *Was the information contained in your medical record (notes, test results, etc.) provided to you in a way that you could understand?*

Shared priorities, but ranked differently

- *Before you left the hospital, did you get all the information you needed in order to know what symptoms or health problems to look out for and* ***who to contact****? (****ranked 3 times higher by patients than healthcare system stakeholders****)*
- *Were the results of your diagnostic tests communicated to you and explained in a timely fashion, and in a way you could easily understand?* ***(ranked twice as high by the patients than the stakeholders)***
- *Were you informed how to escalate care with a rapid response team or how to seek a second opinion?* ***(ranked twice as high by healthcare organizations as patients)***

Divergence between the two groups

Unique to patients

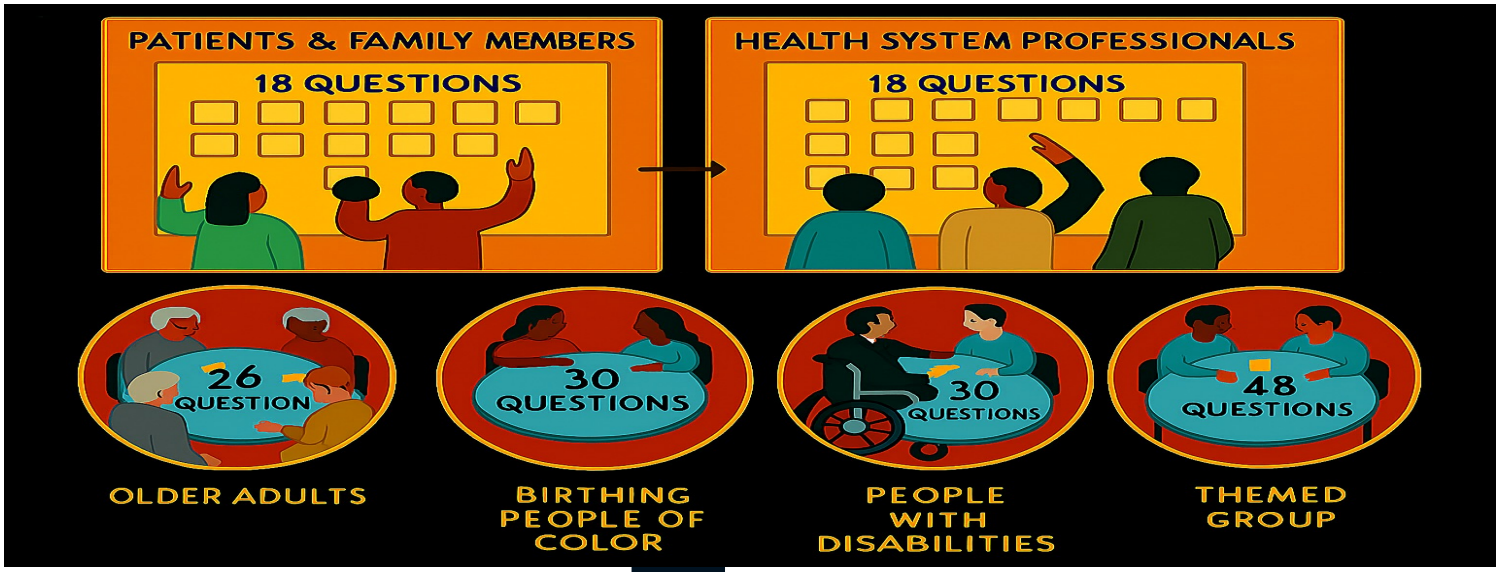
- *Were you given a list of pending test results when you were discharged from the hospital?*

Unique to stakeholder group

- *Did you feel safe?*
- *Did you find errors in your medical records and were there means to correct them?*

Methodology Part Two

Multiple rounds of facilitated discussion and prioritization were conducted to assess the clarity and importance of each question.



Analyzing the ratings provided for each question

Reviewing and incorporating the edits suggested by the focus group

Focus Groups

Older Adults

Birthing People of Color

People with Disabilities

Themed Group

Rosie Bartel

Older Adults (narrowed from 26 to 8 questions)

1. ***Did you (or a family member) experience harm (physical, emotional, psychological, or financial harm) from the care/treatment you received?***
   - If yes, what happened?
   - How did it impact you and your family's health and well-being physically, emotionally, psychologically, or financially?

2. ***Before you left the hospital, did you and/or your family member get all the information you needed in order to know what symptoms or health problems to look out for and who to contact?***

3. ***During discharge, were you given help to set up your follow-up care?***

4. ***Did you understand the discharge follow-up instructions?***

5. ***Were you given clear instructions about your medicines before discharge?***

6. ***Were your family members or support persons included in your care discussions, including at discharge, if you wanted them to be?***

7. ***Were all of your conditions factored into your diagnosis and treatment plan?***

8. ***During your care, were you treated with dignity and respect? TO BE DEFINED***

Gabrielle Scott

Birthing People of Color (narrowed from 30 to 6 questions)

1. ***Did you feel that you were treated differently during your care due to (check all that apply)?***
   - Insurance status, Insurance type, Race, Ethnicity, Age, Disability, Gender, Sexual Orientation, Weight, Disease, Socioeconomic status, Employment Status, Education, Marital status, Family structure, Number of previous children, Identity of my care partner, Identity of my family, Other Factors (specify in the open-ended question)
   - If so, what happened?
   - How did it impact your health and well-being physically, emotionally, psychologically, or financially? (See outcomes slides)

2. ***Did you (or a family member) experience unexpected harm (physical, emotional, psychological, or financial) during or after giving birth?*** *If so, what happened? How did it impact you and your family?*

3. ***Were your cultural and personal preferences respected during your care?***
   Ex. Referral to a culturally affirming doula, provider, advocate, social worker, or Lactation consultant

4. ***Do you feel your mental health needs and life stressors were understood and addressed before, during, and after delivery?***

5. ***Did the dismissal of your or your family member's concerns lead to a delayed diagnosis?***

6. ***Before you left the hospital, did you get all the information you needed in order to know what symptoms or health problems to look out for and who to contact? E.g. connect to a mental health provider, primary care physician, pediatrician***

Lake Murray

People with Disabilities (narrowed from 30 to 5 questions)

1. ***Did you or a family member experience a delayed, missed or wrong diagnosis?*** ☐ No ☐ Yes
   - If yes, what happened?
   - How did it impact you and your family's health and well-being physically, emotionally, psychologically, or financially?

2. ***Were you or your family's concerns or your symptoms dismissed and attributed to your disability without further investigation or diagnostic testing?***

3. ***During all stages of your care, were you offered the accommodations and accessible communication you needed to understand information and participate in decisions?*** ☐ Yes ☐ No, If no, what was missing?

4. ***At any point during your care, did you experience bias or discrimination due to your personal characteristics?*** ☐ No ☐ Yes

5. ***During your care, were you treated with dignity and respect? TO BE DEFINED***

Themed Group

Rated highly by patients beyond the list of 18

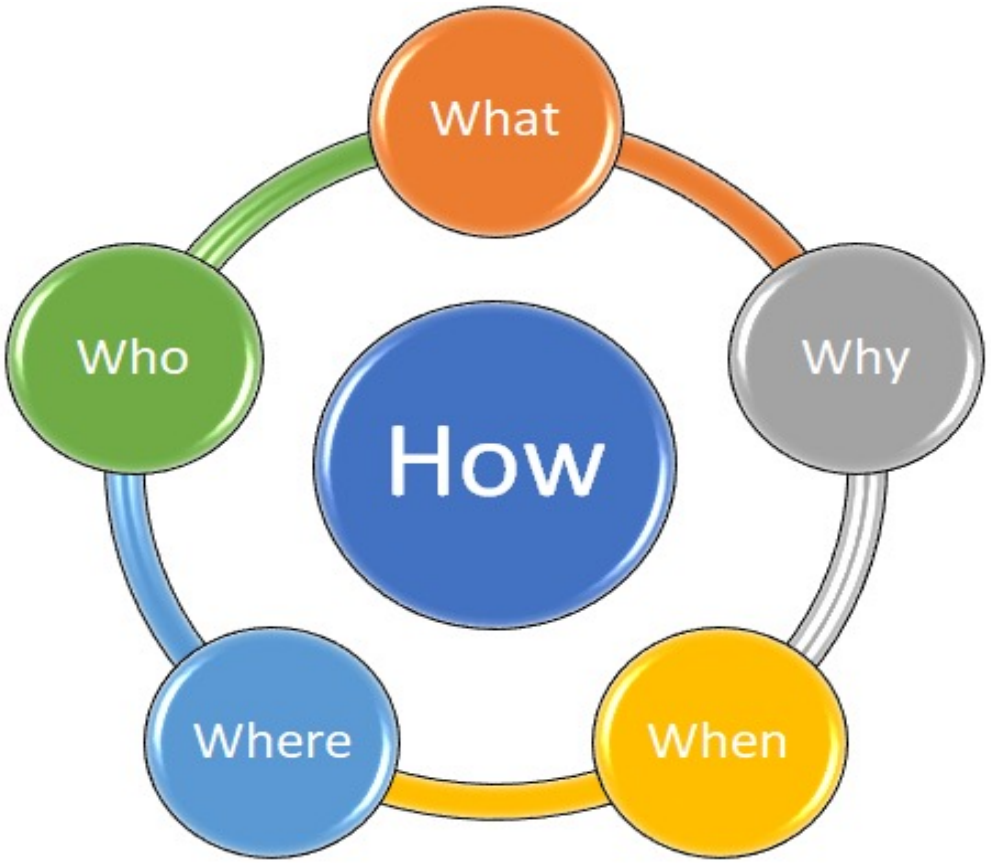
1. *Did the dismissal of your or your family members' concerns result in a delayed diagnosis?*
   - *If yes, what happened?*
   - *How did it impact your and your family's health and well-being physically, emotionally, psychologically, and financially?*

2. *Were you involved in decision-making about your diagnosis and treatment plan?*

3. *Did you receive information about your care in a way that was easy for you to understand, including accommodations for vision, language, or communication needs?*

Health Systems/ Implementation Roundtable

- So now we know what patients would like health care organizations to ask them…. That's the What and Why
- We brought together a diverse group of stakeholders to think about …How



Stakeholder Implementation Roundtable

- Discuss how and when to ask patients these questions in practice.
- Discuss the feasibility of implementation and strategize on overcoming barriers.
- Explore how EHRs and AI can facilitate the collection, triage and analysis of the patient reported measures.
- Further prioritize the PREs and PROs identified in earlier prioritization exercise.

CMS, AHRQ, The Leapfrog Group, Kaiser Permanente, Dana Faber Cancer Institute, UCSF, Geisinger Health, Stanford Health, Johns Hopkins Hospital, Georgetown University Hospital, IHI, Beauregard Health, ECRI, Press Ganey, Oracle, Anesthesia Patient Safety Foundation, National Academy of Medicine

Stakeholders on the Table

Implementation Roundtable Group

Further Prioritized the 9 PREs and PROs identified by both groups

During your hospitalization, did you **experience unexpected harm** from the care and/or treatment that you received? If YES, please describe.

During your hospitalization, did you feel that you were **treated differently due to personal characteristics**? If YES, please describe.

During your hospitalization, did you feel that any of your **concerns were dismissed** by healthcare team members? If YES, please describe.

During your hospitalization, were you **informed of how to report a concern** about your safety, quality of your care, or your experience?

During your hospitalization, were you **informed of how to escalate care** with a rapid response team or how to seek a second opinion?

Overview… what emerges at the top?

Themes
Harm
Reporting/ Escalation
Felt discrimination/ dismissed

System/HCO Challenges
Follow-up, Close the loop?
Legal concerns
Operational - Cost, FTE, Culture

Policy Challenges
Cost
Limitations of Existing Tools
Survey fatigue

Potential Solutions
Implement - through CMS/payors and accreditation agencies
Generate - Financial and Quality RoI through a pilot
Best approaches – Legal within HCOs; engagement with Malpractice Insurers

Potential Action/Commitment/Offer/Ideas from Organizations

CMS	**Encouraged to engage, advocate, do the leg work, propose; PSSM& QIOs avenue**
AHRQ	Explore alignment with HCAHPS survey Qs
Press Ganey	Refine/pilot Qs for potential future testing patient experience surveys (Safety section of the survey); Rounding tool integration; Culture change impact
IHI	Present PIVOT findings at the Forum related to diagnostic safety Explore pilots/engagement with the Leadership Alliance
Oracle	Pilot/Explore adding Qs to Patient portal (pop up before encounter notes/details)
ECRI	Explore alignment/ pilots with PSO clients
Leapfrog	Explore potential of adding successful pilots (PIVOT) as national recommendations
HomeRun/SHM	Explore pilot Qs across research network of hospitals (Hospital medicine)
Anesthesia PSF	Take to Consensus meeting agenda/ explore future guidelines
Beauregard	Explore Qs with PFACs, Senior Leadership – rural context
UW/CRP Collab.	Explore value of these Qs in alignment with CRP programs; culture change
Hopkins	Align with Patient Experience; Centers for Patient Reported Outcome Measures
Kaiser Permanente	Socializing with risk management and patient safety teams, explore
Geisinger	Socializing, exploring alignment/implementation with Patient Experience/Safety

Key learnings: Patients want to report…

Harm and impact to patients and family members, and how the event was handled

Harm from missed, wrong, and delayed diagnosis, and the events that lead to the **misdiagnosis, with "concerns being dismissed" as a key factor**

When care was influenced by personal characteristics
Insurance status, Insurance type, Race, Ethnicity, Age, Disability, Gender, Sexual Orientation, Weight, Disease, Socioeconomic status, and other factors

(Emerging: AI disclosure, options)
If they were informed when AI was used in care, the opportunity to opt out of care that uses AI, the opportunity to report harm from AI, and concerns about the safety of personal data

Key Opportunities

Continue to nurture, grow and engage the PIVOT community

Refine and test prioritized PRE and PRO survey questions, leveraging existing validated tools

Develop PRE and PRO harm measures that don't yet exist, especially those that address: missed, wrong and delayed diagnosis, disrespect/being dismissed, and biases in care

Explore PREs and PROs in new populations or settings (i.e. pediatrics, ED, ambulatory care, long-term care)

Establish a patient-centered research agenda to improve patient safety, diagnosis, and biases in care that is based on the experiences and outcomes that matter to patients identified in Project PIVOT

Explore how EHRs and AI can facilitate the collection, triage, analysis, and reporting of patient reported measures both real time and post-discharge

Project PIVOT **Patient Partners**

- United Spinal Association *
- Disability Rights Oregon *
- National Down Syndrome Society *
- MoMMa's Voices *
- Equity Before Birth *
- National Minority Quality Forum *
- The Human Rights Campaign
- AARP *
- WomenHeart
- National Health Council *
- American Association on Health and Disability *
- Breastfeed Durham *
- Aya Birth & Community Wellness
- Preeclampsia Foundation *
- Hanul Family Alliance *
- The PATIENTS Program *
- Uriel E. Owens Sickle Cell Disease Association of the Midwest
- The Light Collective
- Dia de la Mujer
- Community to Improve Diagnosis in Medicine
- Individual patients and family members with lived experience of patient safety events, diagnostic error, and/or discrimination/bias in healthcare
- Greater National Advocates
- HIV Community
- PFCC Partners
- Sepsis Alliance *
- Patient Safety Movement Foundation
- Society to Improve Diagnosis in Medicine
- The Beryl Institute
- National Partnership of Women and Families
- MedStar Georgetown University Hospital PFACQS®
- Women of Color Wellness Alliance
- Shades of Motherhood *
- Mobilizing African American Mothers through Empowerment (MAAME, Inc.) *
- Amniotic Fluid Embolism Foundation *
- St. Johns Retirement Home, WI *
- Senior Retirement Center, WI *
- Community Campus Partnerships
- Kaiser Permanente PFAC - University of Michigan
- Kaiser Permanente PFAC - California
- Wellstar Hospital PFAC
- Torch Light Health
- Patient No More
- Family Health Initiatives

Stakeholder Partners and Collaborators

- CMS
- AHRQ
- CDC
- OIG
- NQF
- Leapfrog Group
- IHI
- ACEP
- APIC
- Cerner/Oracle
- CoDEx
- ECRI
- CAHPS Consortium
- Press Ganey
- Kaiser Permanente
- UCSF
- Geisenger Health
- Johns Hopkins Hospital
- Dana Farber
- MedStar Health
- Stanford
- University of Maryland School of Pharmacy
- University of Washington
- National Academy of Medicine
- Jewish Healthcare Foundation Fellow
- Anesthesia Patient Safety Foundation
- Beauregard Health

THANK YOU!

Please put a hold on your calendar for an upcoming webinar:

"Advancing Patient and Diagnostic Safety in 2026!"

Wednesday, December 3, 2025
2:00 PM to 3:00 PM ET