

ENGAGING PATIENTS THROUGH SYSTEMATIC COLLECTION OF NARRATIVES ABOUT DIAGNOSTIC PROBLEMS, MISTAKES, AND REMEDIES

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Jane Evered, PhD RN

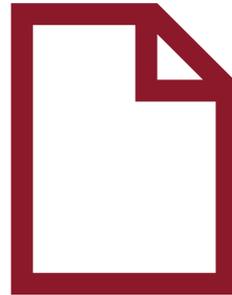


Overview of the Presentation

Focus on people's
experiences with diagnosis



Rigorous elicitation of peoples'
experiences: NEP-DE

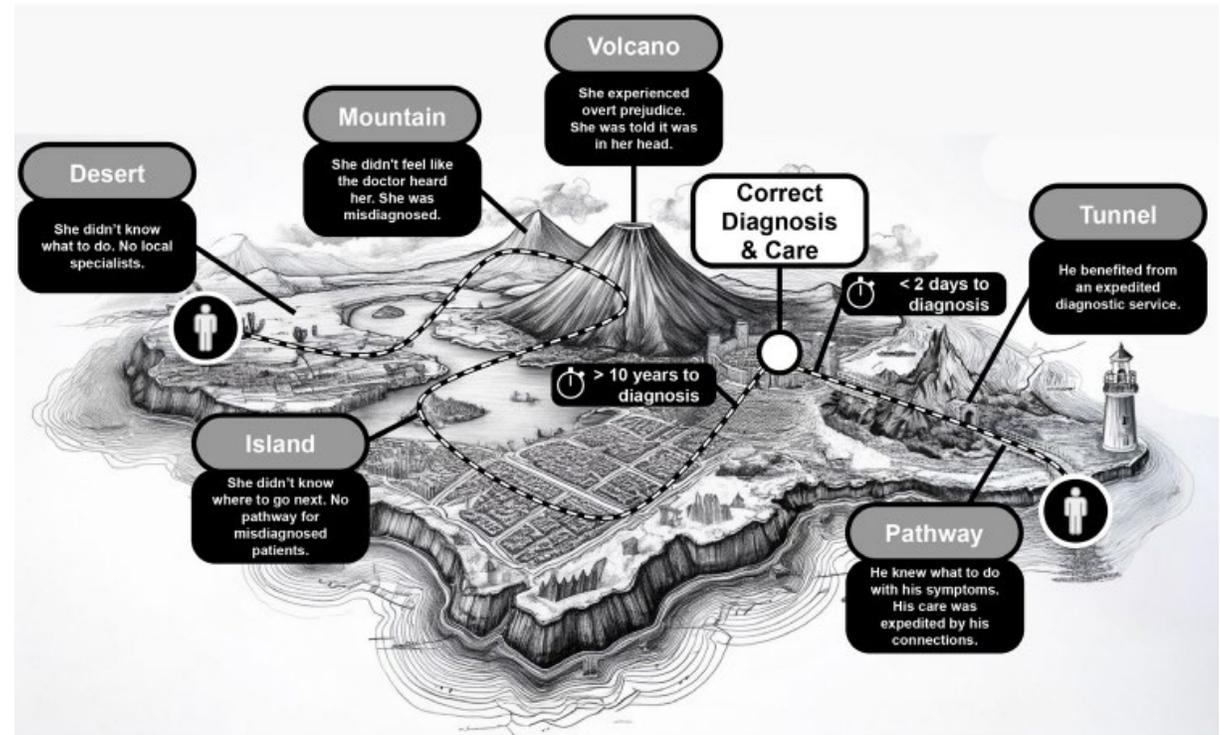


Case example:
Diagnostic Guides



Why focus on peoples' experiences and creative ideas?

- People with lived experiences are the connecting thread across diagnostic odysseys
- Diagnosis is inherently and inevitably a team effort with the person and care partner(s) seeking care at the center
- People with lived experiences have many creative ideas for system change



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Engaging people in the systematic collection of narratives

Complete:

Provide a full picture of the experiences that matter to the patient describing them

Balanced:

Accurately reflect both positive and negative aspects of the patient's experiences

Meaningful:

Convey a story that is coherent to others and allows them to assess its relevance to their own care

Actionable:

Contains concrete information that can be used to make health and health care better

Representative:

Capture experiences from patients across a range of health status and demographic characteristics

Useful:

Told in formats (e.g., video or audio recorded) that allow them to be re-purposed in multiple ways

The NEW ENGLAND JOURNAL of MEDICINE

Taking Patients' Narratives about Clinicians from Anecdote to Science

Mark Schlesinger, Ph.D., Rachel Grob, Ph.D., Dale Shaller, M.P.A., Steven C. Martino, Ph.D., Andrew M. Parker, Ph.D., Melissa L. Finucane, Ph.D., Jennifer L. Cerully, Ph.D., and Lise Rybowski, M.B.A.

Documented Utility and Impact

HSR Health Services Research

Breaking Narrative Ground: Innovative Methods for Rigorously Eliciting and Assessing Patient Narratives

Rachel Grob ^{1 2}, Mark Schlesinger ³, Andrew M Parker ^{4 5}, Dale Shaller ⁶, Lacey Rose Barre ⁷, Steven C Martino ⁸, Melissa L Finucane ⁵, Lise Rybowski ⁹, Jennifer L Cerully ⁵

HSR Health Services Research

Evaluation of a protocol for eliciting narrative accounts of pediatric inpatient experiences of care

Steven C. Martino PhD ¹  | Kerry A. Reynolds PhD ¹ | Rachel Grob PhD ² |

“Nothing Is More Powerful than Words:” How Patient Experience Narratives Enable Improvement

Rachel Grob, PhD; Yuna S.H. Lee, MPH, PhD; Dale Shaller, MPA; Emily Warne, BS; Sasmira Matta, MHS; Mark Schlesinger, PhD; Ingrid M. Nembhard, MS, PhD

Quality Management
in Health Care

THE
MILBANK QUARTERLY
A MULTIDISCIPLINARY JOURNAL OF POPULATION HEALTH AND HEALTH POLICY

What Words Convey: The Potential for Patient Narratives to Inform Quality Improvement

RACHEL GROB,* MARK SCHLESINGER,[†]
LACEY ROSE BARRE,[‡] NAOMI BARDACH,[§]
TARA LAGU,^{||} DALE SHALLER,[#]
ANDREW M. PARKER,** STEVEN C. MARTINO,**
MELISSA L. FINUCANE,** JENNIFER L. CERULLY,**
and ALINA PALIMARU**,^{††}

HSR Health Services Research

Assessing an innovative method to promote learning from patient narratives: Findings from a field experiment in ambulatory care

Dale Shaller MPA  Ingrid Nembhard PhD, MS, Sasmira Matta MHS, Rachel Grob PhD, Yuna Lee PhD, MPH, Emily Warne BS, Richard Evans MA, Daniel Dicello MA, Maria Colon MPH, Annery Polanco MPH, Mark Schlesinger PhD ... [See fewer authors](#) ^

Narrative Elicitation for Diagnostic Experiences: The NEP-DE

- Q6A** Please tell us more **about the diagnostic mistake or problem that happened**. What were the key steps, how were choices made, who was involved, and how did you experience these interactions with doctors and other clinicians.
- Q6B** Please describe how well or poorly you and your doctors **communicated** about your diagnosis. How well did doctors listen, explain the diagnosis, respond to questions and describe next steps in clarifying the diagnosis?
- Q6C** After you realized that there was a problem with the diagnosis, what, if anything, did the doctors and other clinicians do or say that **made things better**? This could include things that improved your health, your medical care, or how you felt about the diagnostic experiences.
- Q6D** After you realized that there was a problem with the diagnosis, what, if anything, did the doctors and other clinicians do that **made things worse**? This could include anything that negatively impacted your health, your medical care, or how you felt about the diagnostic experiences.
- Q6E** After you realized there was a diagnostic mistake or problem, what, if anything, did you **wish had been done** by doctors, other clinicians, or others in the healthcare system to improve the situation?

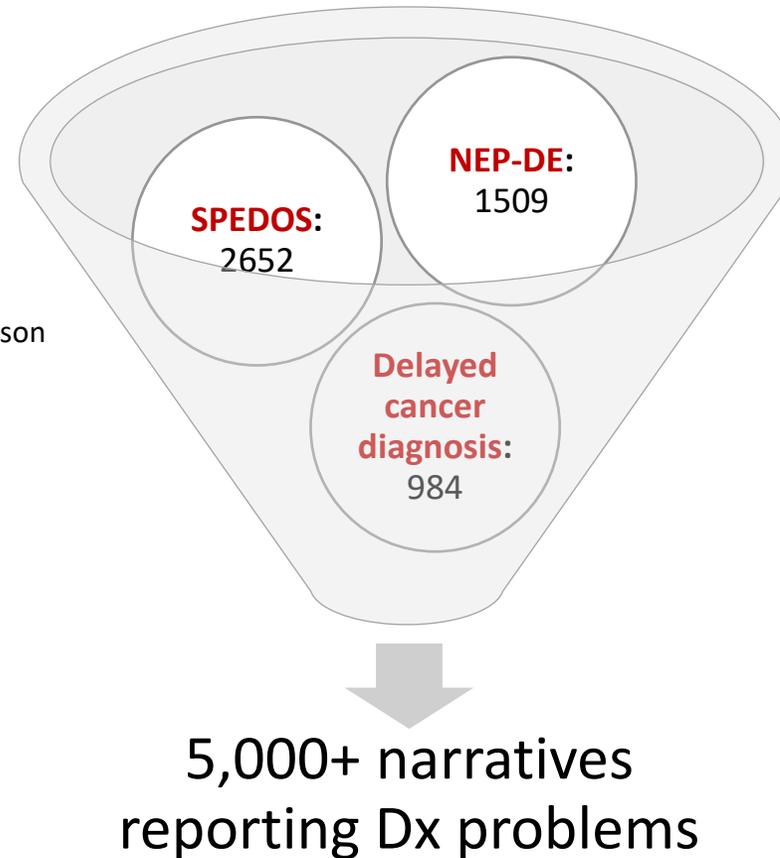
Narrative Elicitation for Diagnostic Experiences: The NEP-DE

- Q6F** Please explain how, if at all, these diagnostic experiences affected your life and your medical care **in the months immediately following** the mistake or problem with the diagnosis. How were you feeling about these experiences?
- Q6G** How, if at all, did the diagnostic experience affect the ways in which you **currently use the health care system**? Did it impact when and how you seek medical care? How you interact with doctors and other clinicians?
- Q6H** Are there things you understand now about your diagnosis or the diagnostic process that you **wish you had known sooner**? Please explain.
- Q6I** Did you have a doctor or other clinician or other person who you felt was a **reliable source of guidance and support** during the diagnostic process? If so, how did you come to rely on this person and how did this person help?
- Q6J** Sometimes aspects of people's **background, culture, identity or health needs** make their diagnostic experiences better or worse. How, if at all, do you think these factors impacted your experiences associated with the mistake or problem with diagnosis?

Learning from narratives about diagnostic experiences

A tale of 3 surveys

(Publications to date: Gleason et al., 2026; McDonald et al., 2025; Gleason et al., 2024)



Learning from narratives about diagnostic experiences

Understand how systems might use narratives:

An example from middle managers (Grob et al., 2024)

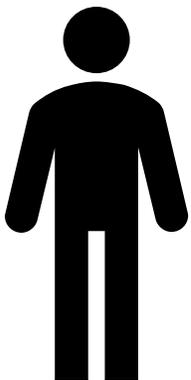
Catalyzing **structural**
improvement projects
(ex. workflow)

Catalyzing **relational**
changes
(ex. communication)

Examples of structural issues suggested by narratives

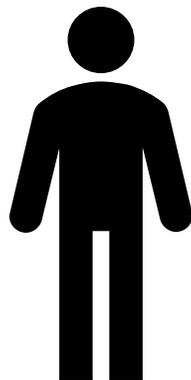
Visit length:

"I liked my PCP and had a good rapport. But [blinded system]'s strict time limit per visit did not make it feasible to trust them."



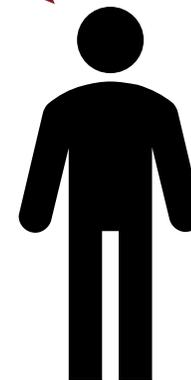
Organizational structures:

"The system is extremely siloed by different medical specialties (not a holistic approach) and is not well-suited to helping patients resolve complicated medical issues"



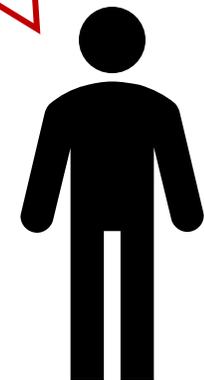
Triage workflows:

"The PCP office didn't make me an appointment...the front medical office is not trained to triage medical problems...all I needed was an appointment to see a doctor."



Clinical guidelines:

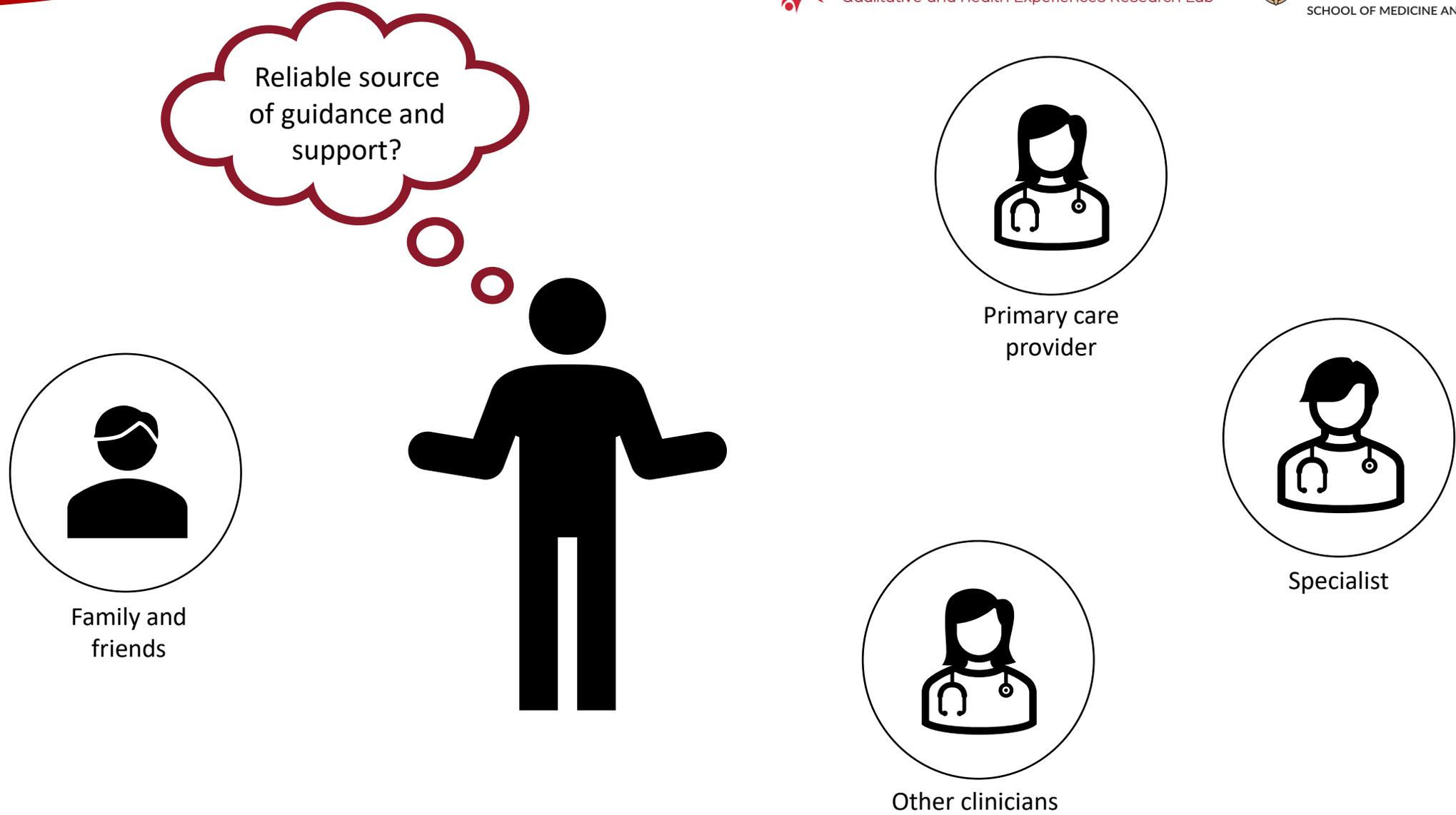
"I understand the concern with antibiotic resistance these days but at my age, people my age group, don't have the youth and energy to fight infections...shouldn't be denied more aggressive treatment as we age."



Example of **relational changes** suggested by narratives:

A deeper dive into diagnostic guides

“Did you have a clinician or other person who you felt was a **reliable source of guidance and support** during the diagnostic process? If so, how did you come to rely on this person and how did this person help?”



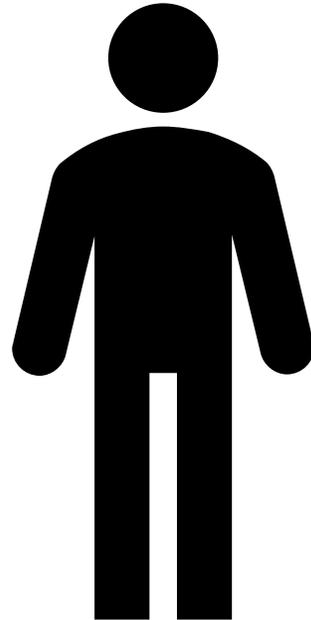
1/3 at least one diagnostic guide

(1/3 stated they did not have a diagnostic guide

1/3 did not respond with sufficient detail)



Family and
friends



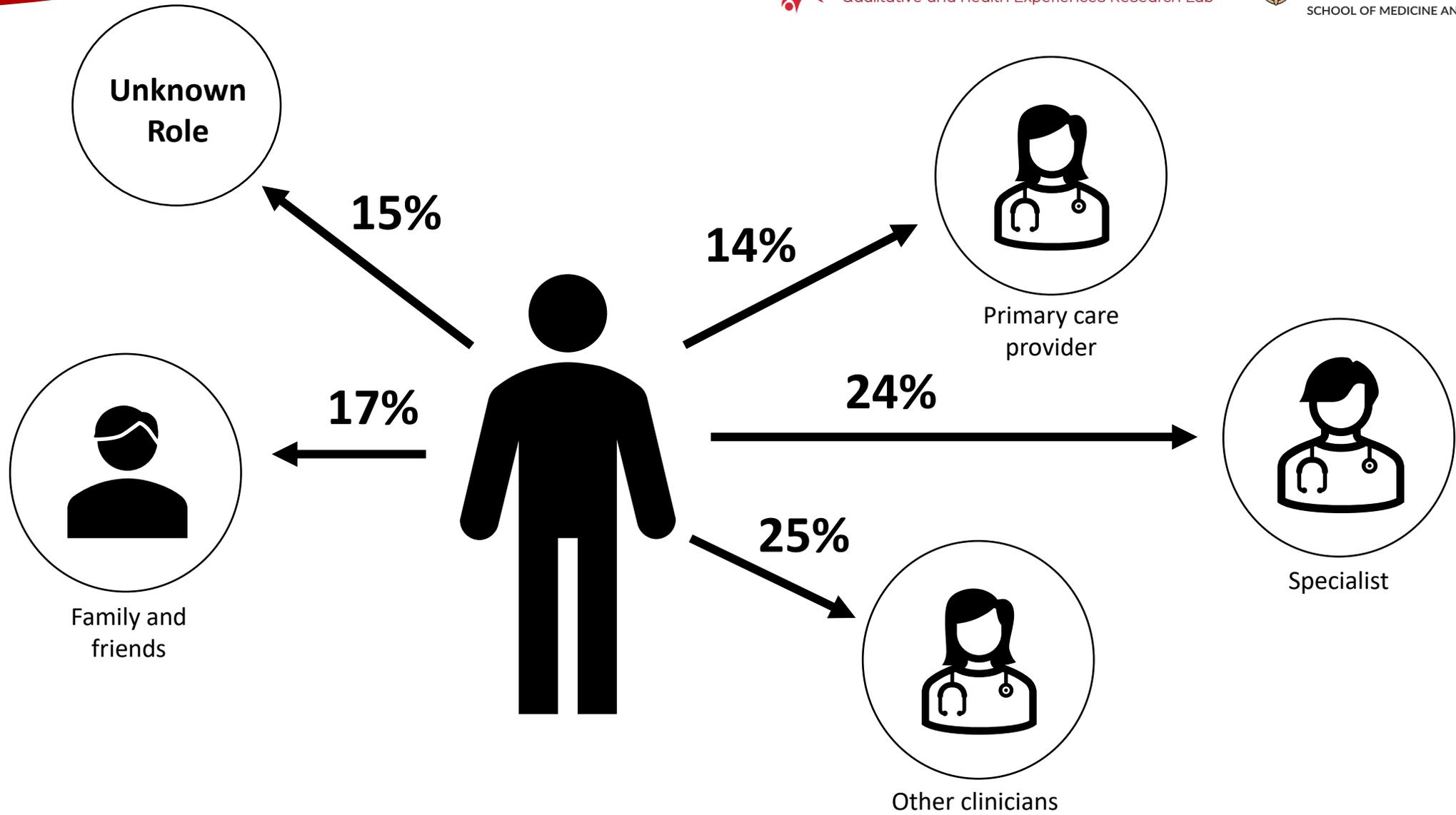
Primary care
provider



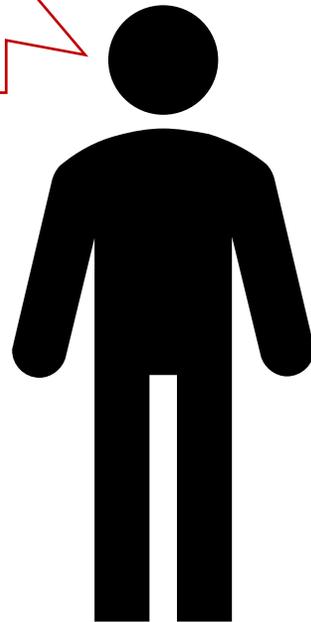
Specialist



Other clinicians



Exhibits competence
“I felt very confident that he was
thorough and made a valid
decision.”



Primary care
provider



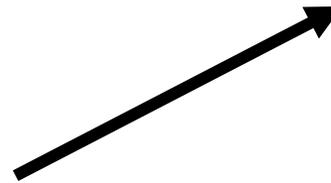
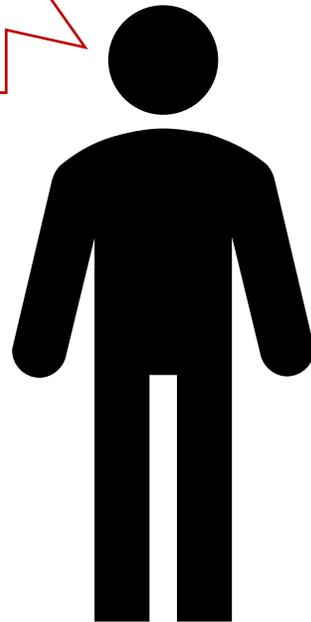
Specialist



Other clinicians

Listens deeply with compassion

“My doctor really listened and didn't
need proof for what I was going
through.”



Primary care
provider

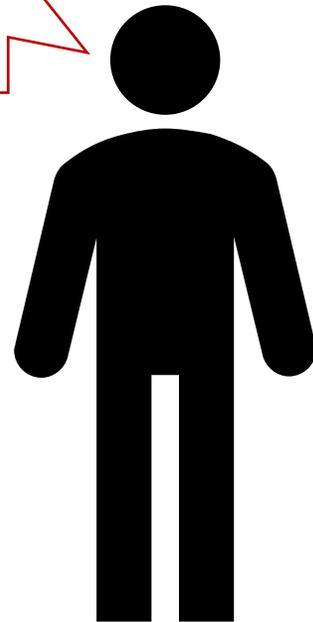


Specialist



Other clinicians

Provides accompaniment
“(She) promised to walk with me
and support me through the
process.”



Primary care
provider



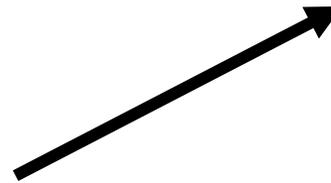
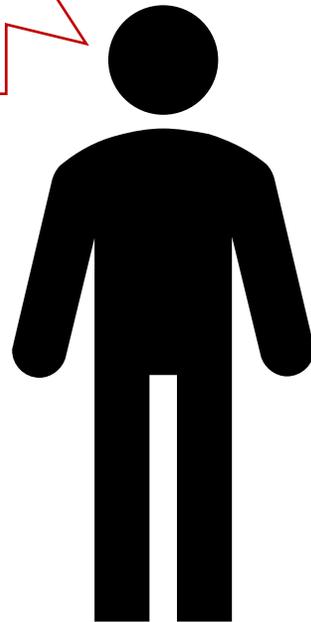
Specialist



Other clinicians

Demonstrates trustworthiness

“I trusted his opinion and he guided me through the process by ordering tests and reading the results and explaining them to me.”



Primary care
provider



Specialist



Other clinicians

Why do diagnostic guides matter?

Clinician diagnostic guides are associated with:

Resolutions of
diagnostic mishap

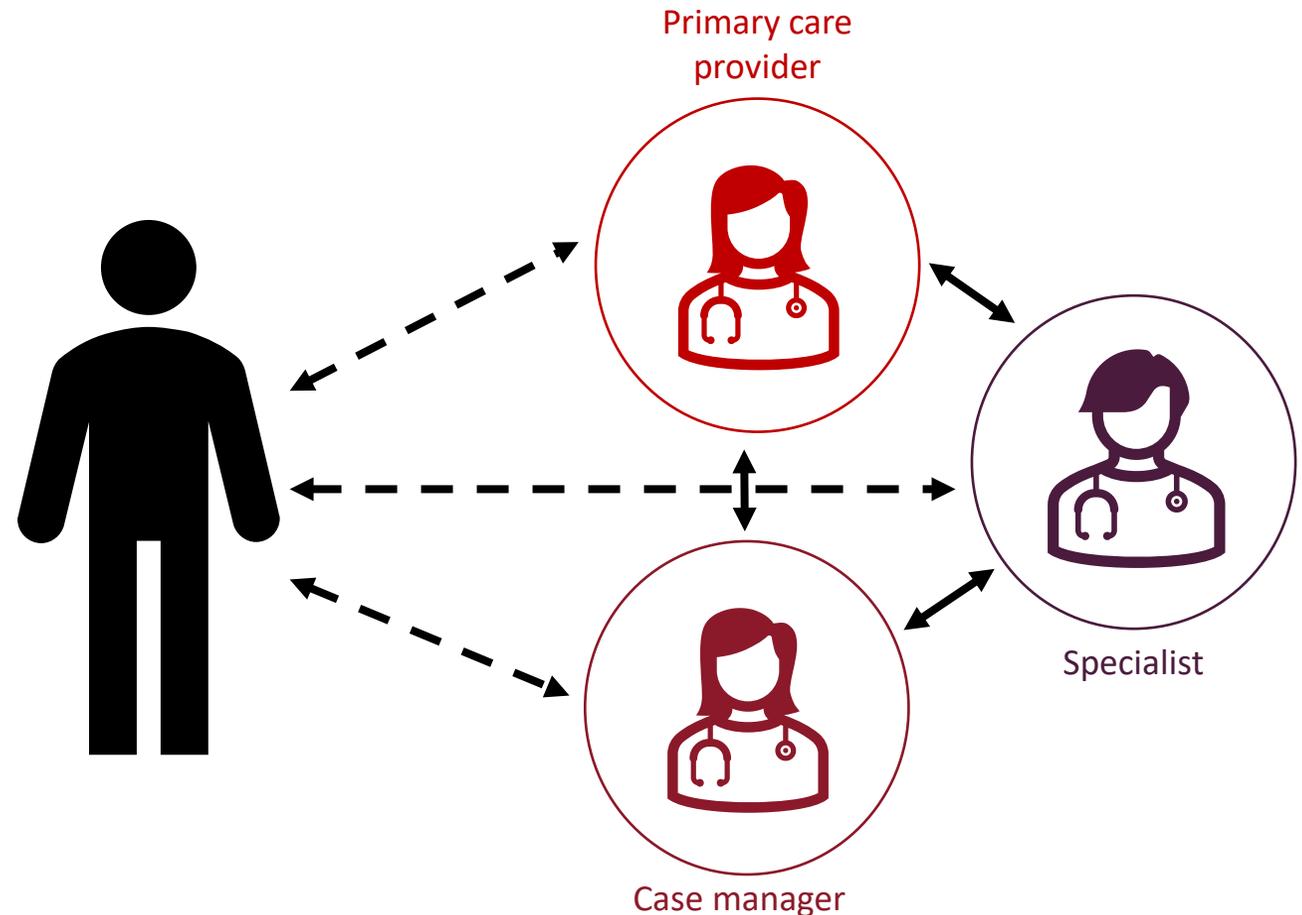
Buffering short term
and long-term loss of
trust in clinicians

Reducing avoidance
of medical care

***From regression models controlling for:** demographic variables (age, gender, race, education level, disability status, household income, urban/rural), whether or not have a regular source of medical care, whether had experienced multiple diagnostic mishaps, number of years since mishap, mishap type (problems vs. mistakes), COVID-19 impact, and the number of settings involved in the diagnostic process

Structural changes to support relational changes?

- How can systems support access to and role of diagnostic guides?
- How systems support people in engaging their teams, particularly when multi-team systems cross settings, specialties, and even institutions?
- How can systems support coordination across clinicians?



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**Questions, comments,
feedback, ideas?**