

ELICITING PATIENT NARRATIVES FOR INSIGHTS ABOUT IDENTITY IN THE DIAGNOSTIC PROCESS

National Academies of Medicine

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BREAST CANCER

Overview

[Discovering You Have Cancer](#) ▼[Decisions about Treatment](#) ▼[Healthcare and Treatment](#) ▼[Perceptions of Care Quality](#) ▼[Living with Breast Cancer](#) ▼[Advocacy](#) ▼[Messages to Others](#) ▼[People's Profiles](#)[Resources and Information](#)[Credits](#)

MERLE



Age at interview: 37

Outline: Merle was initially diagnosed with Stage 2B breast cancer in their 30s and had a partial mastectomy and radiation. Within two years, they were diagnosed with metastatic breast cancer and had surgery for bone metastases, for which they currently take oral and endocrine therapies. Both diagnoses were delayed, thus advocacy has been the through-line in Merle's cancer story. Creativity and having a multi-layered spiritual core also keep Merle going.

Background: Merle is a mixed Korean/White, non-binary writer and artist who lives alone in a large city in the Midwestern.

Breast cancer type: Metastatic breast cancer

Merle says narrative studies honor complex identities and allow people to define themselves out of pre-determined boxes.



Overview of the Presentation

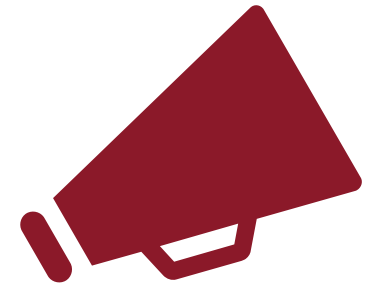
Rigorous Elicitation of
Patient Narratives



Narrative Elicitation for Diagnostic
Experiences: The NEP-DE



Hearing from Patients
in Their Own Words



Rigorous Narrative Elicitation

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 & 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

RESEARCH ARTICLE

 **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


Original Scholarship

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

❖ **Developed and refined over three waves**

- Nationally representative internet sample (NORC)
- Elicited narratives compared to intensive interviews

❖ **Findings reported here:** Combined sample

- Diagnostic experiences from 1283 respondents
- Respondent mix: patients (55%) and care partners (45%)



**Data reported here from
final two waves**

March 2023 - June 2023

Narrative Elicitation for Diagnostic Experiences: The NEP-DE

What happened

Q6A In your own words, tell us more about the diagnostic mistake or problem that happened. Please describe what happened, who was involved, and what might have led up to the problem.

*How well
communicated*

Q6B Now, please tell us more about how well you and your providers communicated throughout the diagnostic process. This could include talking and listening to one another, along with any other forms of communication.

*What made
things better*

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.

*What made
things worse*

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?

*Wish had
been done*

Q6E After you realized there was a diagnostic problem, what, if anything, do you wish had been done by doctors, clinicians, or others in the healthcare system to improve the situation?

Narrative Elicitation for Diagnostic Experiences: The NEP-DE

*Immediate
aftermath*

Q6F Please explain how, if at all, this diagnostic mistake or problem affected your life and your medical care in the months immediately following when you realized that there was a problem. How were you feeling about these experiences?

*Current care
seeking and
interactions*

Q6G How, if at all, did the experience of this diagnostic mistake or problem 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?

*Wish you
knew*

Q6H Are there things you understand now about your diagnosis or the diagnostic process that you wish you had known sooner? Please explain.

*Guide star
clinician*

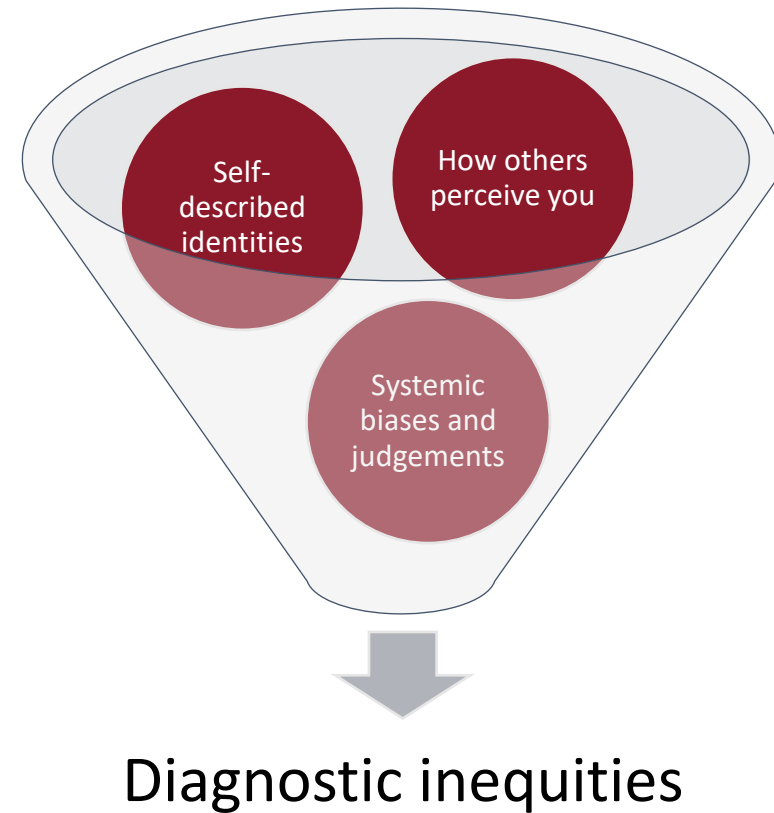
Q6I Did you have a clinician or other person who you felt was a reliable source of guidance and support during the diagnostic process? If so, how did you come to rely on this person and how did this person help?

Identity

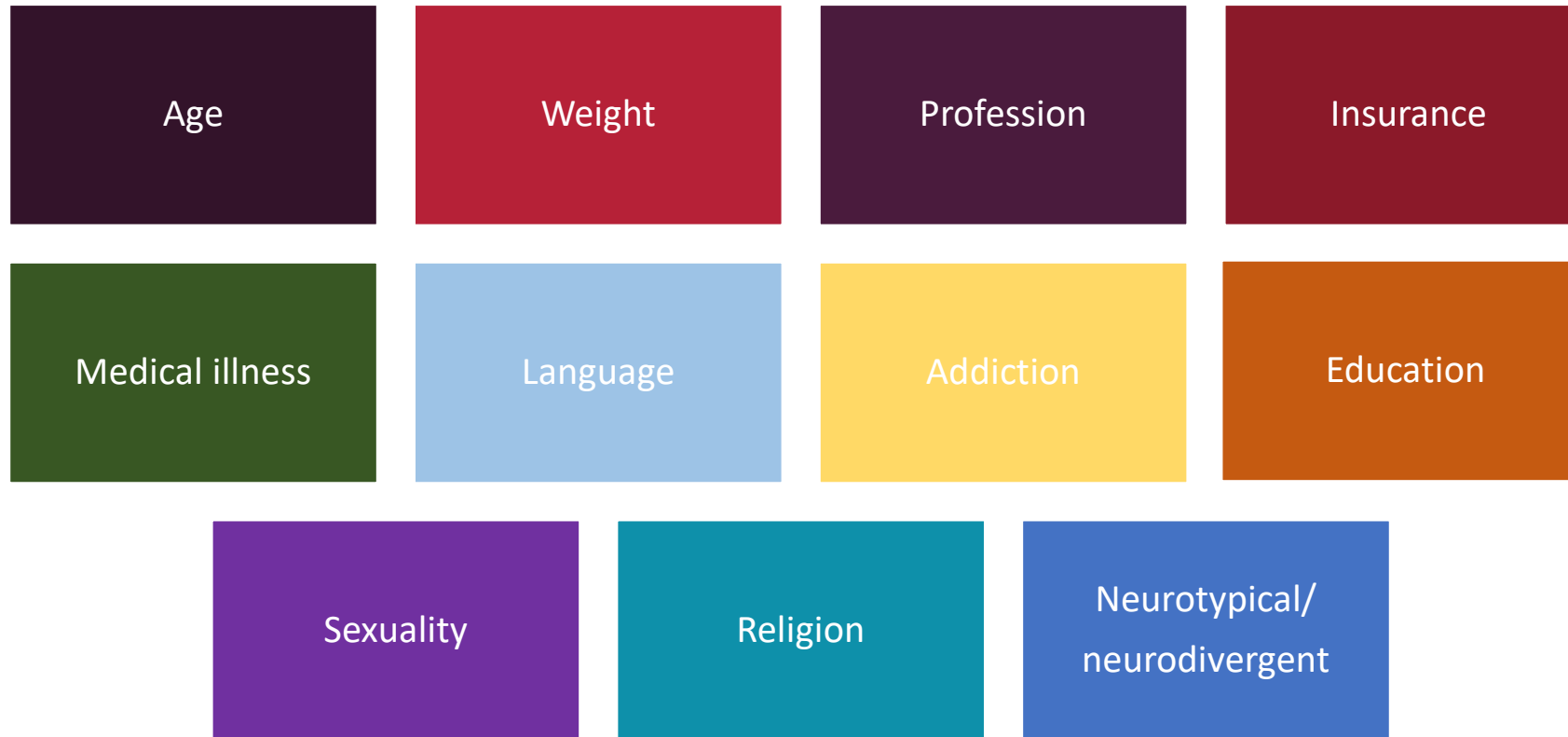
Q6J Sometimes aspects of people's background, culture, identity or health needs make their diagnostic experiences better or worse. How, if at all, do you think these factors impacted your diagnostic experience?

Asking About the Role of Identity in Diagnosis

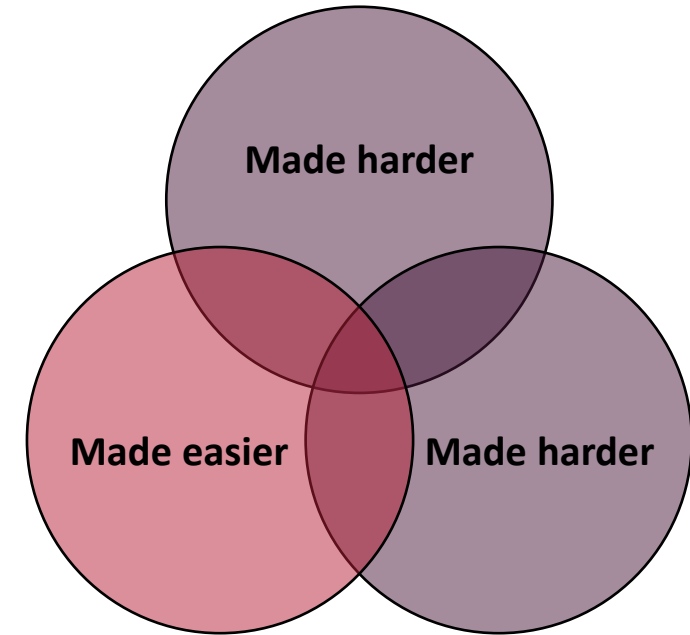
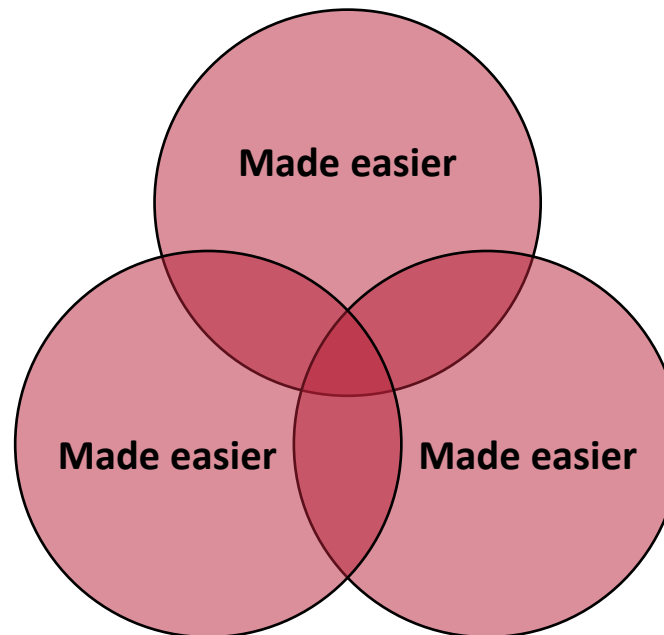
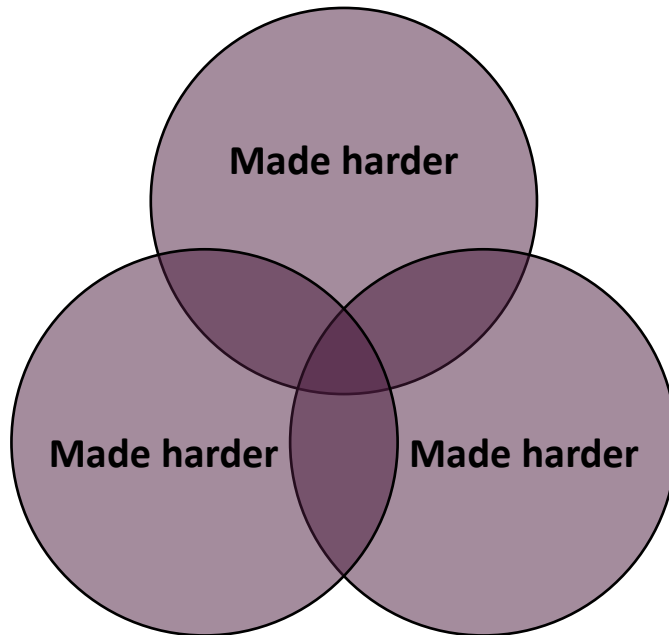
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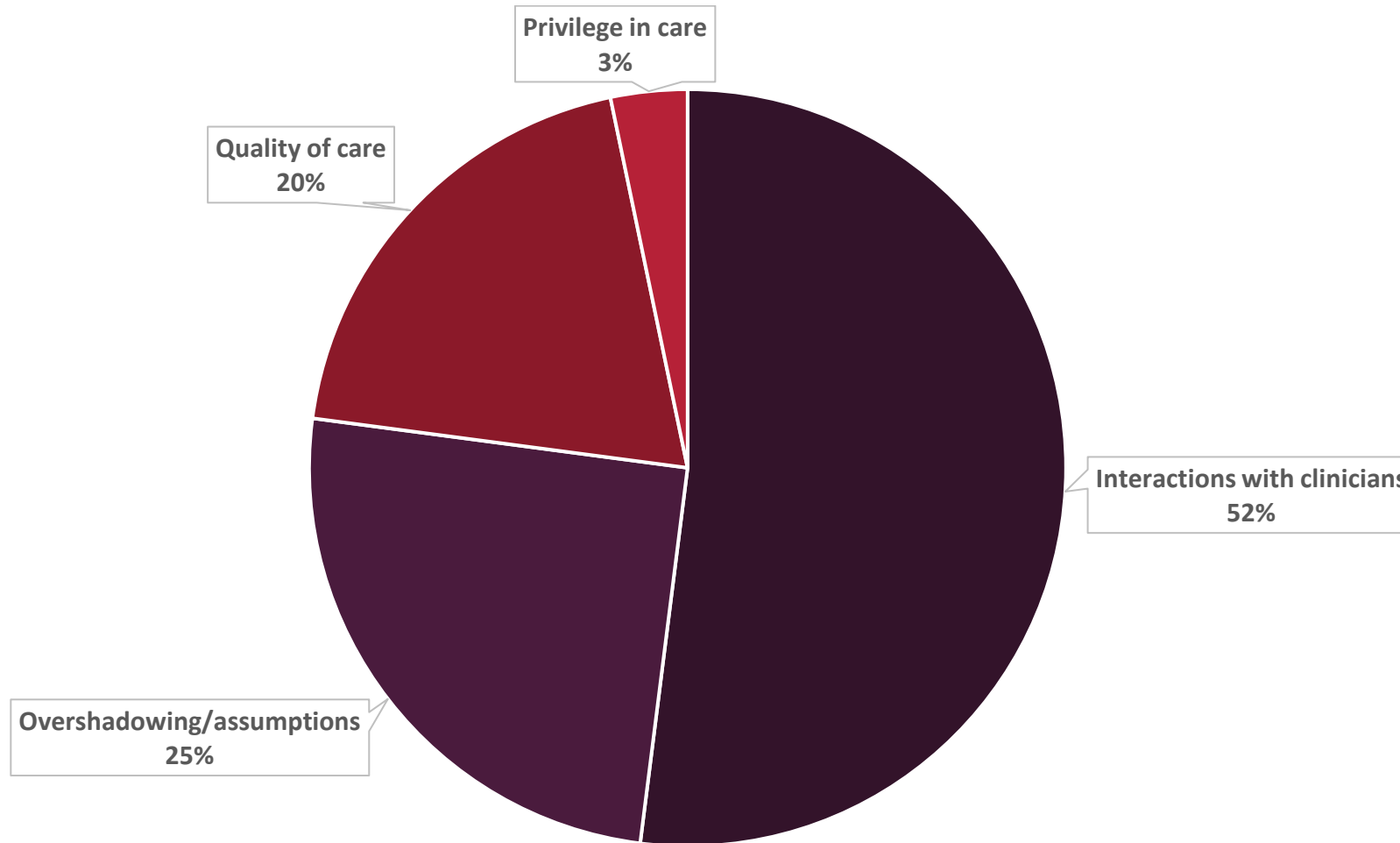
Aspects of Identity Reported to Impact Diagnostic Process



Intersectionality



Diagnostic (In)equity Themes



Interactions with Clinicians

Being ignored/not
listened to
(46 segments)

"I feel if I was a white woman more extensive test would have been done and my concerns would have been heard."

Not being believed/taken
seriously
(43 segments)

"I'm a woman, which means I'm not taken seriously by many people. I'm now a senior, which exacerbates the problem. I'm white, though, so have that "privilege" - I feel so terrible about minorities b/c I'm sure their treatment issues are even worse than mine."

Uncaring, hostile, or
condescending
communication
(34 segments)

"I was verbally abused. I was called names accused of being a difficult patient and because I am legally blind my competency was questioned."

Being abandoned
(12 segments)

"I honestly believe the doctor just didn't know how to treat a trans person and didn't want to be involved in my care so he just went with the easiest option and sent me off."

Quality of Care

Accessing Care (6 segments)

“Because I am poor and uninsured and do not live in a big city, this is the only healthcare available to me and so I have to put up with it despite how lacking it's been.”

Not Doing Enough (32 segments)

“Neither in the care team did enough research or took the time to review all available notes in files and labs, or confer with others in the medical field to help solve the problem. I really think multiple people dropped the ball. In that length of time, I had multiple labs which were not discussed with me.. What is going on? I am wondering if there is a conspiracy to just let you die if you or **older than 65 and black!!!!!!**”

Unnecessary Care (10 segments)

“My providers were terrible and just wanted to run the same tests over and over to Slam my insurance...**Blacks folks** are historically mistreated in the medical field. This was no different.”

Overshadowing/Assumptions (n=69)

"You must be stupid despite your **two bachelor degrees**, you must be exaggerating your pain because **you're a "woman,"** it must be **your weight** because we all know **if you're fat then ALL of your health problems are caused by your weight**, even the ones that started when your BMI was actually in the normal range... that's how the diagnostic process works."

"Some what I think **my race** play a part in the mistakes that had. Feel that **they thought I was there just for drugs** not help."

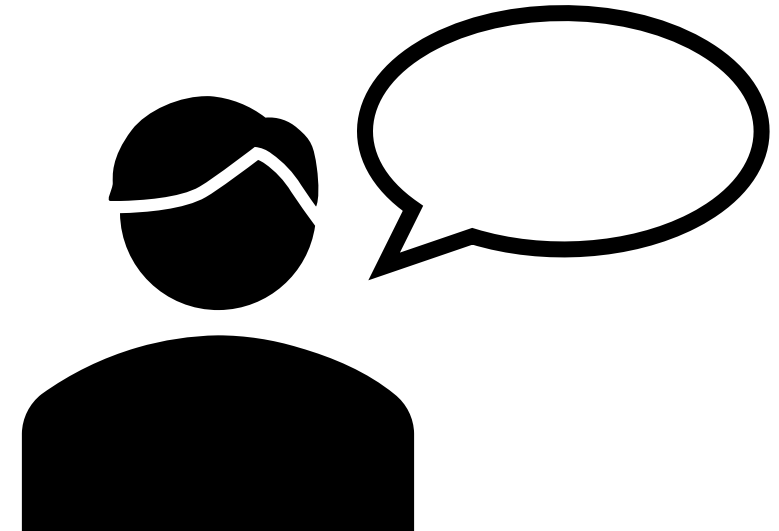
Forthcoming



Further field testing
(AHRQ-funded)



Publications
(under-review and in
development)



In-depth interview-
based study

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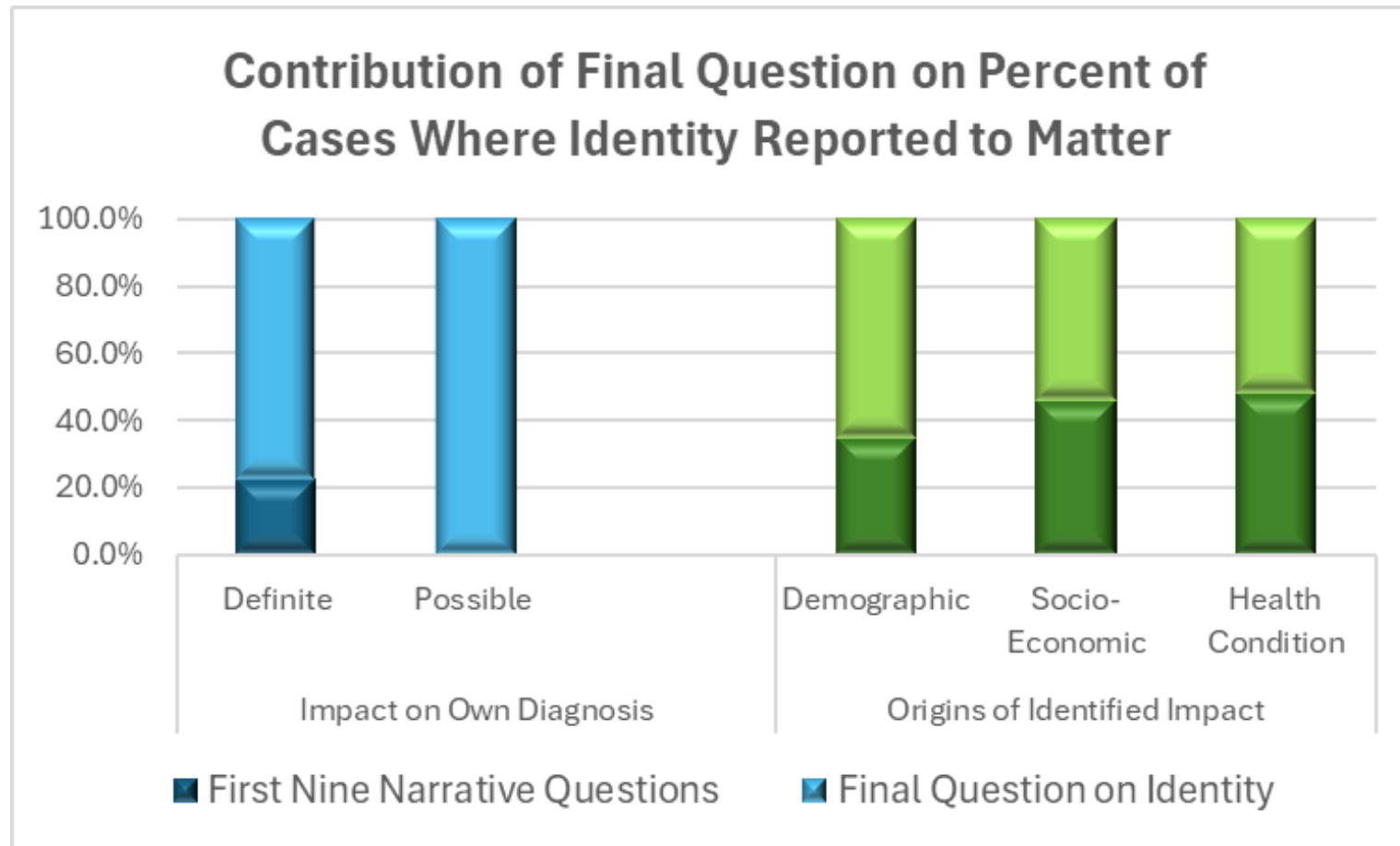
Funding:



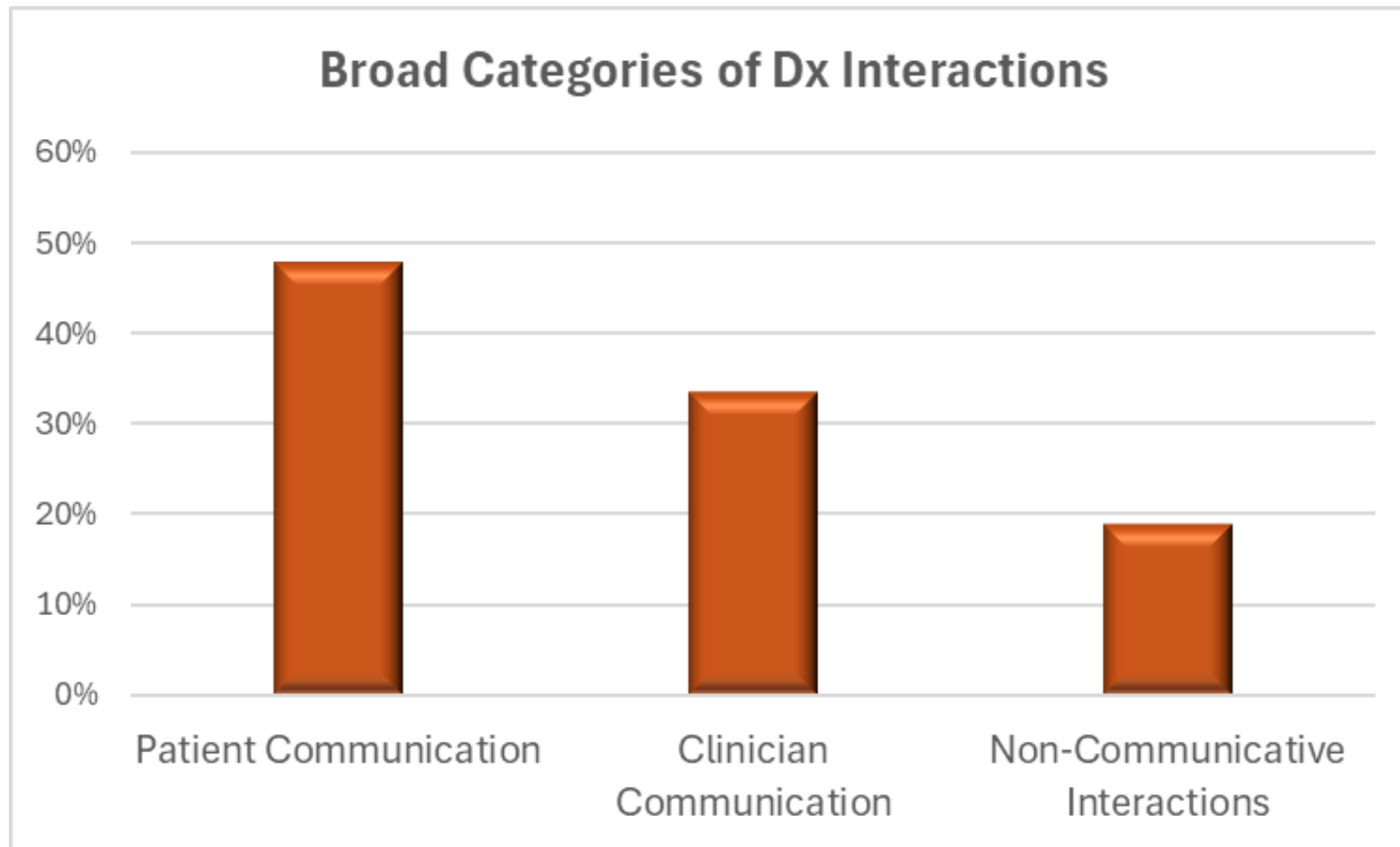
**Questions, comments,
feedback, ideas?**

Appendix

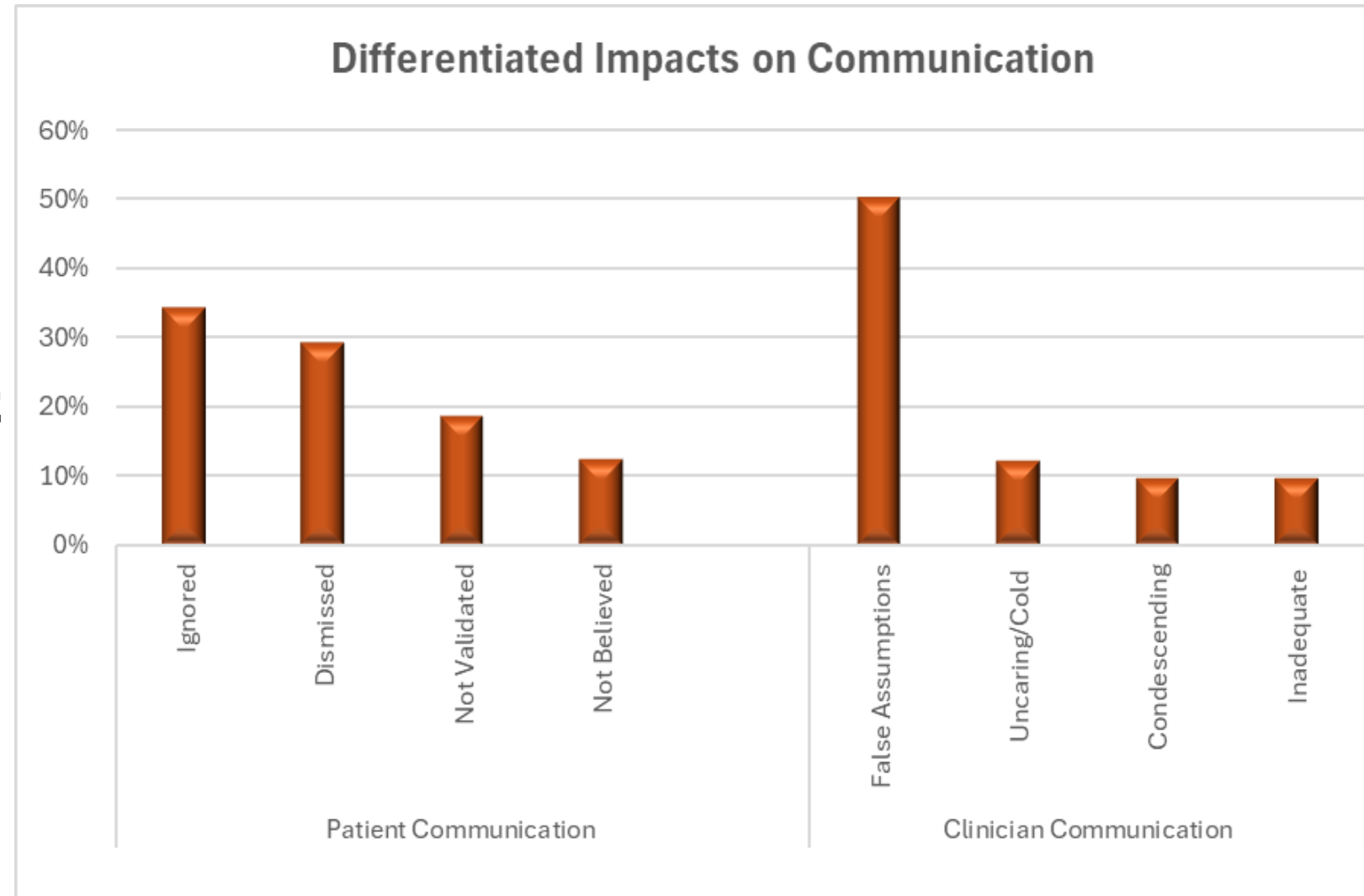
Asking About the Role of Identity in Diagnosis: Reporting



Aspects of Diagnostic Process Affected by Patient Identity



Aspects of Diagnostic Process Affected by Patient Identity



Privilege in Care

“As a **White, educated, articulate American male**, I think I have **regularly received careful, correct diagnoses.**”

I hold a lot of privilege as a **cis white woman, employed full-time** - **I don't believe these impacted my care.**

“Because I was a **white, cisgender, heterosexual, college-educated, and middle-class patient whose first language is English**, I believe my cultural identities **did not impede my diagnostic experiences**. I recognize that I was lucky to have the time, resources, and knowledge I needed to advocate for my medical needs. On the other hand, I quickly noticed a pattern in my research that female-specific health problems have been under-studied. I also suspected at times that my symptoms were taken less seriously because I am **a woman** (“Do you think the pain could be more psychological?”).”