We ask, "Does that make sense?" and patients say, "Yes“

How self-reported understanding undermines individual and population health

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Forum on Rural Population Health

May 15, 2026

Disclosures/Conflicts of interest

- I have no financial conflicts to disclose.

Session objectives

- ❑ Recognize the hidden nature of lower health literacy.
- ❑ Identify the limitations of parents' and caregivers' self-reported understanding.
- ❑ Describe a simple, quick, acceptable, cost-effective means of objectively assessing understanding for better outcomes.

Outline

- Health literacy
- The “hidden epidemic” of confusion, misunderstanding, and missing information
- Ways of “knowing” that patients and their caregivers understand
- Teach-back
- Discussion

- **Personal health literacy** – the ability to find, understand, and use information and services to inform health-related decisions and actions.

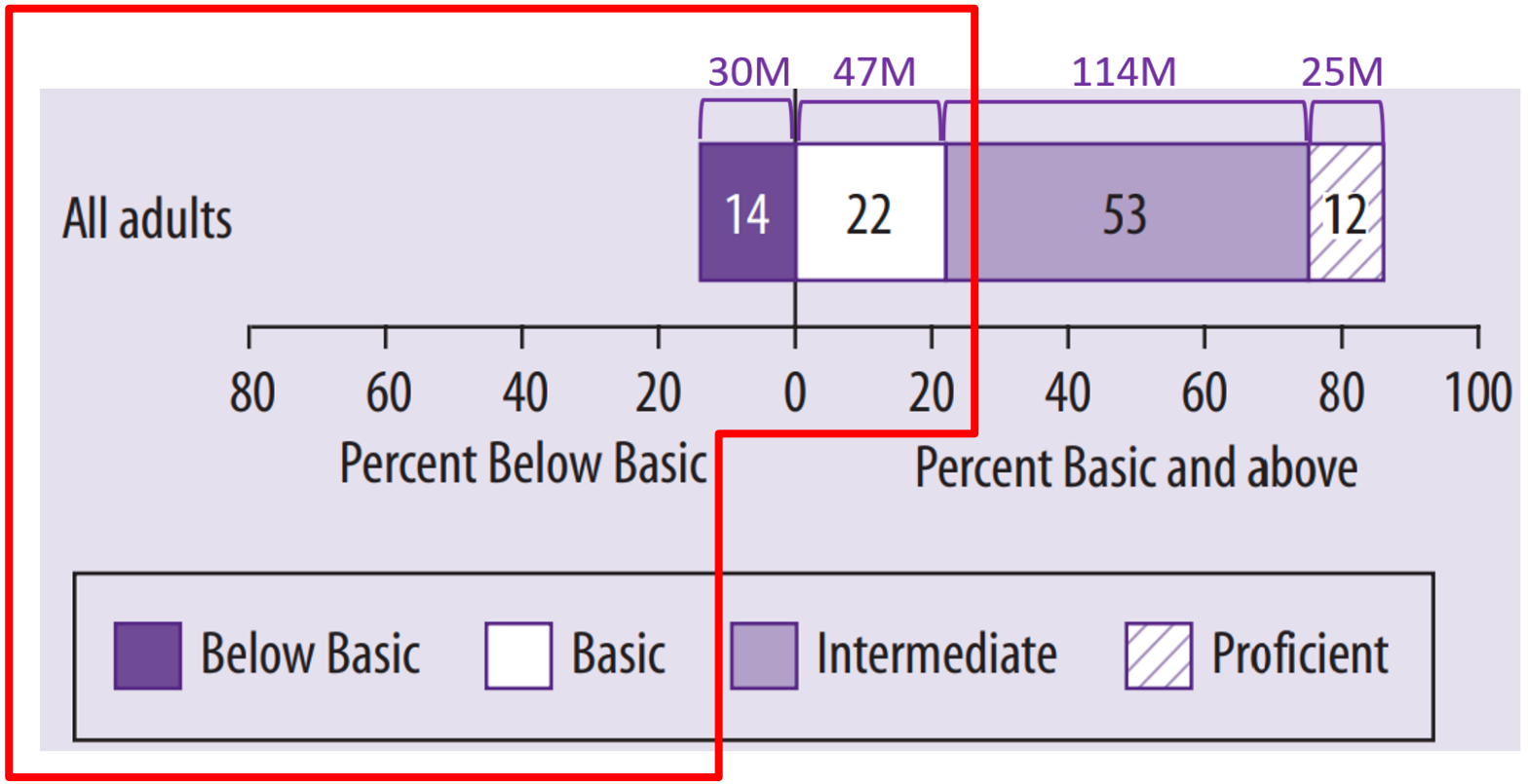
Health literacy

- **Organizational health literacy** – the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions.

(HHS, 2020)

36% of U.S. adults have low health literacy at baseline

National Assessment of Adult Literacy



(Kutner et al, 2006)

Health literacy in rural communities

- In developed countries like the U.S., average health literacy tends to be lower in rural communities.

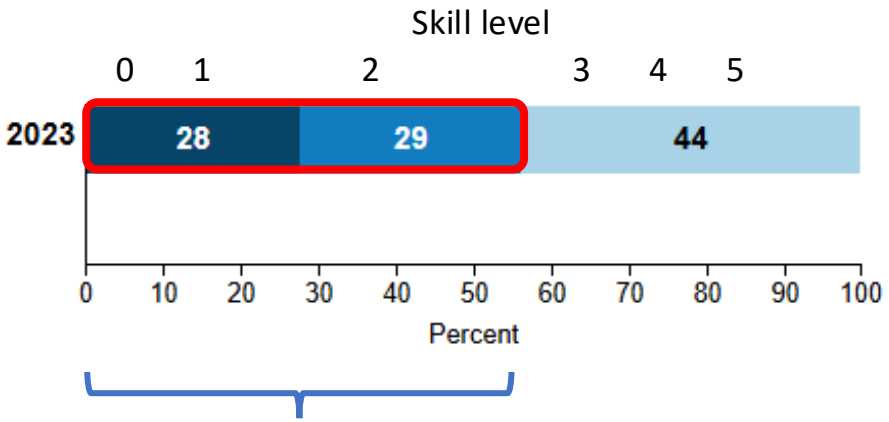
- Likely due to factors such as lower average education, and higher average age.

(Aljassim & Ostini, 2020)

Literacy and numeracy of U.S. adults, 2023

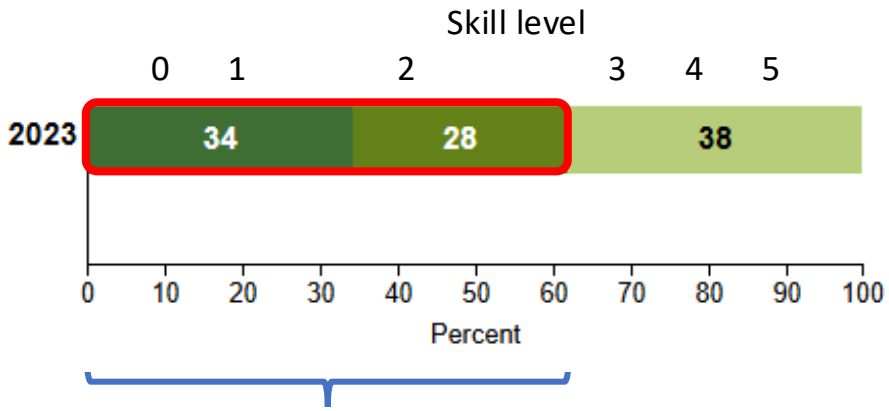
(Program for the International Assessment of Adult Competencies)

GENERAL LITERACY



57% level 0-2

NUMERACY



62% level 0-2

(US Dept of Education, 2024)

The “hidden epidemic” of confusion, misunderstanding, and missing information

We know that patients…

- Experience misunderstanding, confusion, and informational gaps.

(Klingbeil & Gibson, 2018; Sommer et al, 2018)

- Remember about half of what they hear in clinic.

(Kessels, 2003; Laws et al, 2018; McCarthy et al, 2012)

- Don’t know what their main problem was up to half the time after leaving the hospital.

(Chappuy et al, 2012; Horwitz et al, 2013; Makaryus & Friedman, 2005; Olson & Windish, 2010)

- Overestimate/overreport understanding of jargon.

(Chow et al, 2021; Neill et al, 2020; Zhu & Engulìdanos, 2019)

- Overestimate understanding of their care, and are poor at self-assessment

(Sommer et al, 2018)

But we also know…

- Lower literacy is associated with feelings of shame and embarrassment.

(Wolf et al, 2007)

- Patients hide their lack of understanding due to shame.

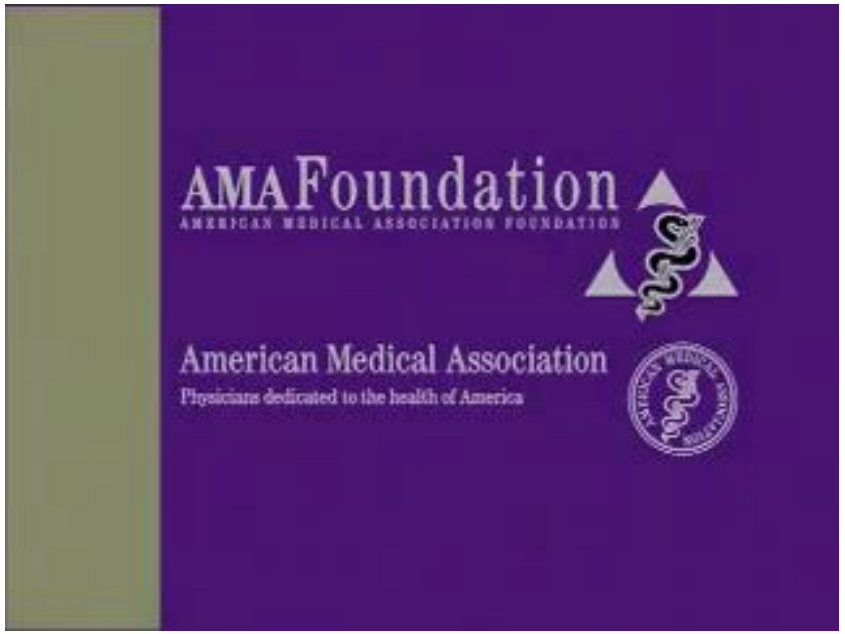
(Baker et al, 1996; Lyons & Dolezal, 2024; Parikh et al, 1996)

- Lack of understanding can be masked by verbal skills.

- Physicians are poor at recognizing low health literacy.

(Bass et al, 2002; Coleman et al, 2013)

Stigma and shame



"Help Patients Understand" (AMA Foundation, 2010 [excerpts]) https://www.youtube.com/watch?v=cGtTZ_vxjyA

Patients overestimate their understanding of jargon

- Clinicians use a lot of undefined jargon with patients and families.

(Charpentier et al, 2021; Links et al., 2019; Miller et al., 2022; Wood & Gupta, 2021)

- Doctors grossly underestimate their use of jargon.

(Howard et al, 2013)

- Patients are often unfamiliar with the meaning of terms like “fasting,” “fracture,” “benign,” and “negative” and “positive.”

(Hume et al, 1994; Cosic et al, 2019; Hayes et al, 2018; Gotlieb et al, 2022)

- Or may be familiar with the term but lack full comprehension of its meaning.

(Barker et al, 2014)

- Will say they understand a term, but then not be able to demonstrate understanding.

(Chow et al, 2021; Neill et al, 2020; Zhu & Engulìdanos, 2019)

Patients overestimate their understanding in general

Systematic review of 28 studies concluded that hospitalized adults:

- Have poor knowledge about their:
  - Diagnoses
  - Care plan
  - Medications
  - Names and roles of care team members
  - Discharge instructions
- Are poor at self-assessing their own understanding.

Or maybe they're just over-reporting!

(Sommer et al, 2018)

You can’t tell by looking

- Doctors overestimate the health literacy skills of their patients.

(Bass et al, 2002)

- Screening for low health literacy is not appropriate.

(Paasche-Orlow & Wolf, 2008)

Ways of “knowing” that patients and their caregivers understand

4 moments of misleading feedback

- ❑ Nonverbal body language and verbal “continuers.”
- ❑ Soliciting questions (e.g., *“Do you have any questions?”*)
- ❑ Asking, *“Do you understand?” “Does that make sense?”* or *“Do we have a good plan?”*
- ❑ HCAHPS* survey items: *“How often did your nurses and doctors speak with you in a way that was easy to understand?”*

(*Hospital Consumer Assessment of Healthcare Providers and Systems)

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Nonverbal body language and “continuers”

Nonverbal cues

- Nodding
- Squinting
- Pursing lips
- Raising eyebrows
- Smiling
- Frowning

Verbal “continuers”

- “Hmm”
- “Mmm hmm”
- “Yep”
- “OK”
- “I see”
- “Go on”

Nonverbal body language and “continuers”

Jargon	Jargon type
Infection	Medical vernacular
Sterile drape	Medical vernacular
Cerebrospinal fluid space	Technical
Introducing	Medicalized English
Bacteria	Medical vernacular
Precautions	Unnecessary synonym

A medical student discussing informed consent for lumbar puncture with a standardized patient and mannequin infant, OHSU, 2025. Used with permission of the participants.

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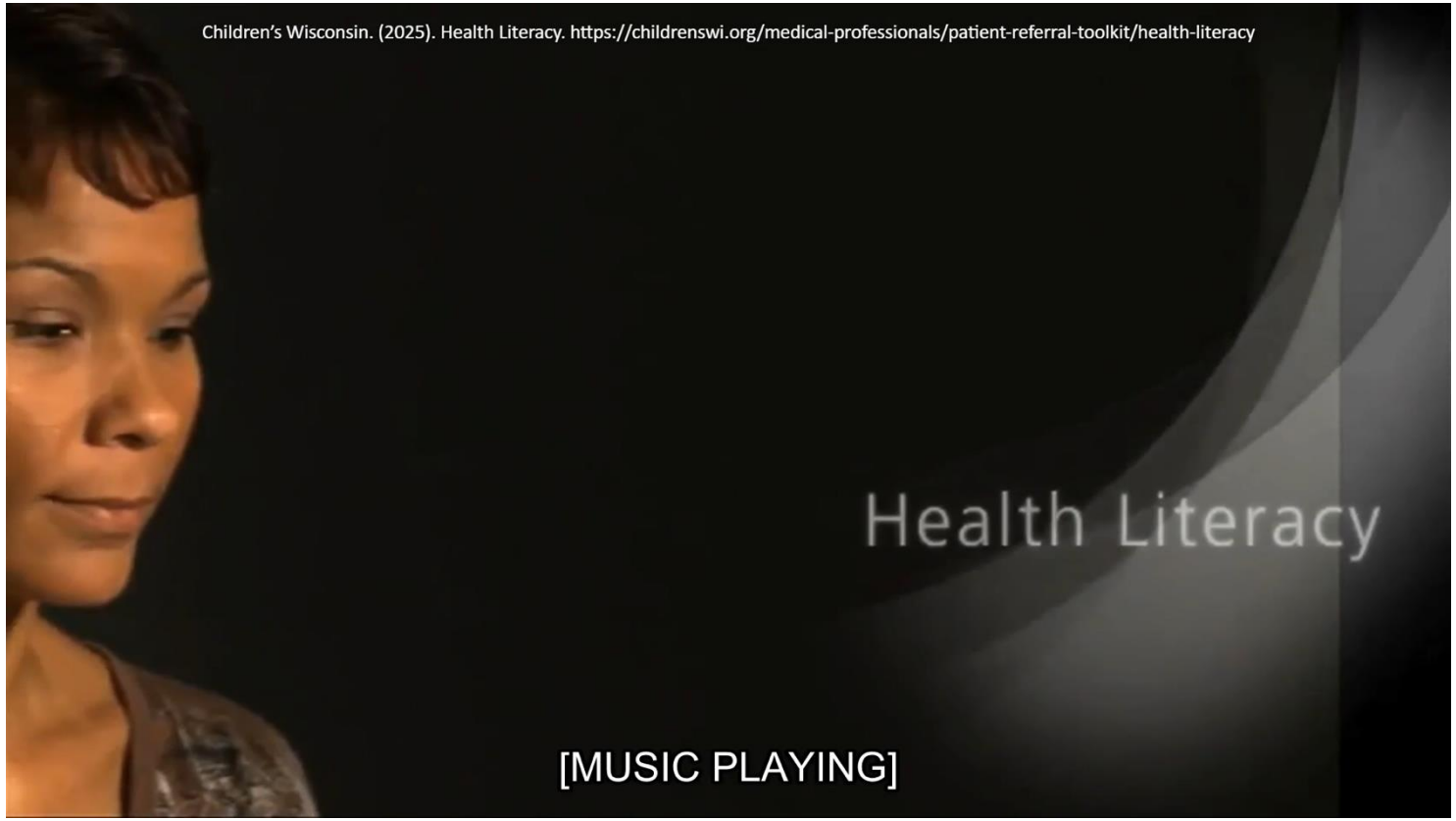
Soliciting questions

“Before the end of the visit, the doctor will usually ask, ‘Do you have any questions?’ That is usually the precise moment that my mind goes completely blank. Every question I can think of seems silly or embarrassing. I know the doctor is busy so I don’t want to ‘bother’ him/her by taking up too much of their time. I really do not want to look stupid or ignorant. So, I say nothing, smile and the doctor leaves the room…”

(Prairie Doc, 2025)

Rita’s story



Children’s Wisconsin. (2025). Health literacy – Rita’s story (1:42 excerpt). https://childrenswi.org/medical-professionals/patient-referral-toolkit/health-literacy

“What questions do you have?”

NCHealthLiteracy. (2015). Teach back in a cardiology practice. https://www.youtube.com/watch?v=e5jxeZWM3tw [excerpt]

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"Do you understand the plan?"

- Closed-ended questions get a *"Yes"* or *"No"* answer:
  - *"Does that make sense?"*
  - *"Do you understand?"*
  - *"Do we have a good plan?"*
- Likely to get a *"Yes,"* even when there is confusion.

(Graham & Brookey, 2008; Lin et al, 2015)

IHA. (2025). Always Use Teach-back Toolkit! https://teachbacktraining.org/media-library/videos/ [1:06]

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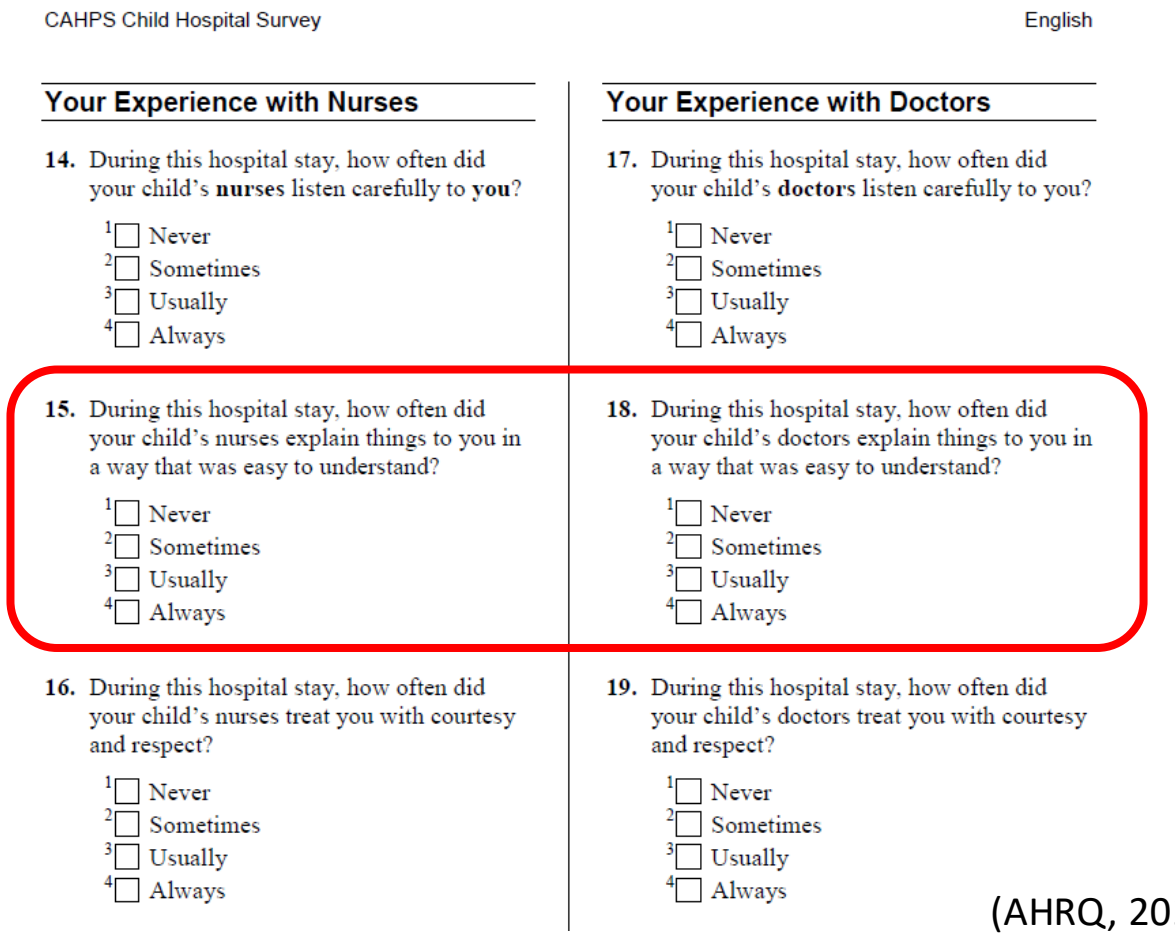
Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)® survey

- The Centers for Medicare & Medicaid Services requires hospitals to track patient and caregiver experiences with the HCAHPS® survey.



CAHPS Child Hospital Survey English

Your Experience with Nurses

14. During this hospital stay, how often did your child's **nurses** listen carefully to **you**?

1 ☐ Never
2 ☐ Sometimes
3 ☐ Usually
4 ☐ Always

15. During this hospital stay, how often did your child's nurses explain things to you in a way that was easy to understand?

1 ☐ Never
2 ☐ Sometimes
3 ☐ Usually
4 ☐ Always

16. During this hospital stay, how often did your child's nurses treat you with courtesy and respect?

1 ☐ Never
2 ☐ Sometimes
3 ☐ Usually
4 ☐ Always

Your Experience with Doctors

17. During this hospital stay, how often did your child's **doctors** listen carefully to you?

1 ☐ Never
2 ☐ Sometimes
3 ☐ Usually
4 ☐ Always

18. During this hospital stay, how often did your child's doctors explain things to you in a way that was easy to understand?

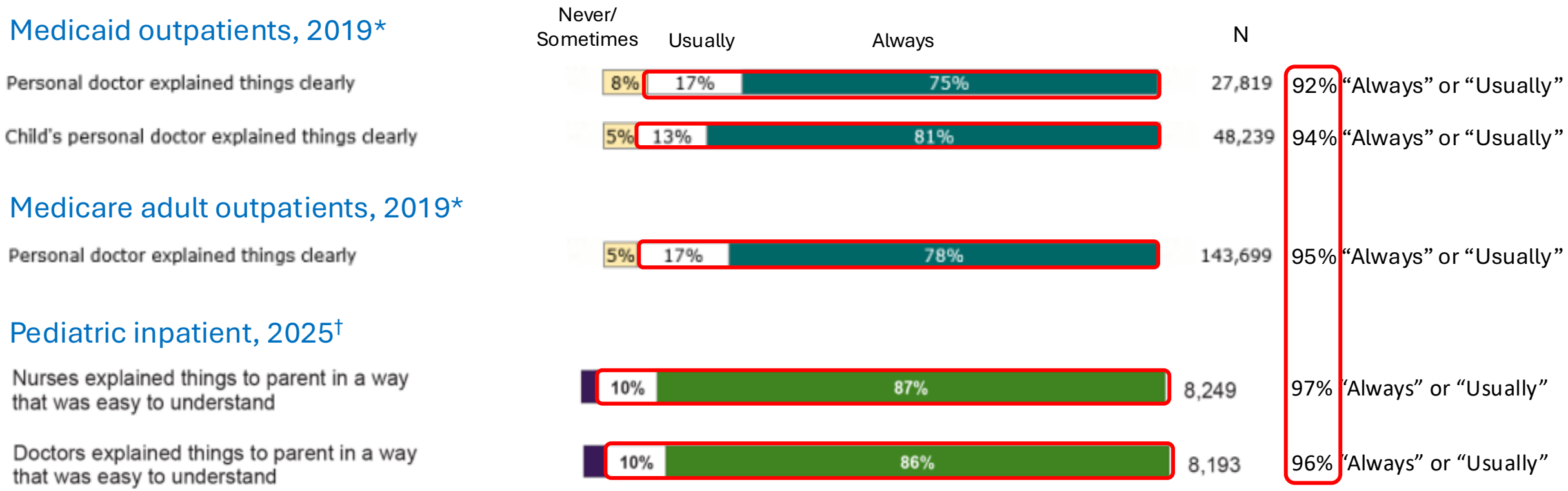
1 ☐ Never
2 ☐ Sometimes
3 ☐ Usually
4 ☐ Always

19. During this hospital stay, how often did your child's doctors treat you with courtesy and respect?

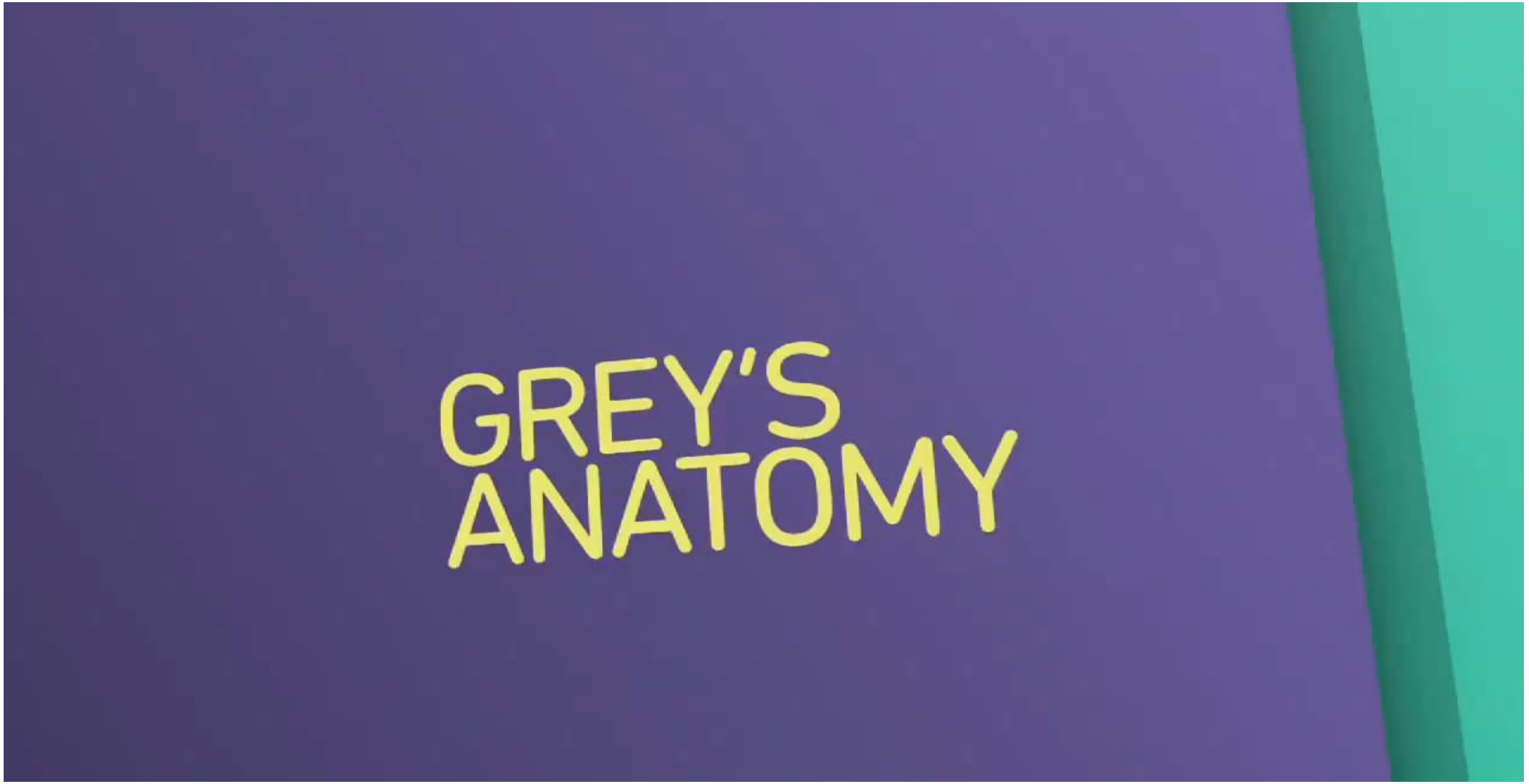
1 ☐ Never
2 ☐ Sometimes
3 ☐ Usually
4 ☐ Always

(AHRQ, 2025a)

Outpatient (CAHPS®) and hospital (HCAHPS)® ratings overestimate understandability

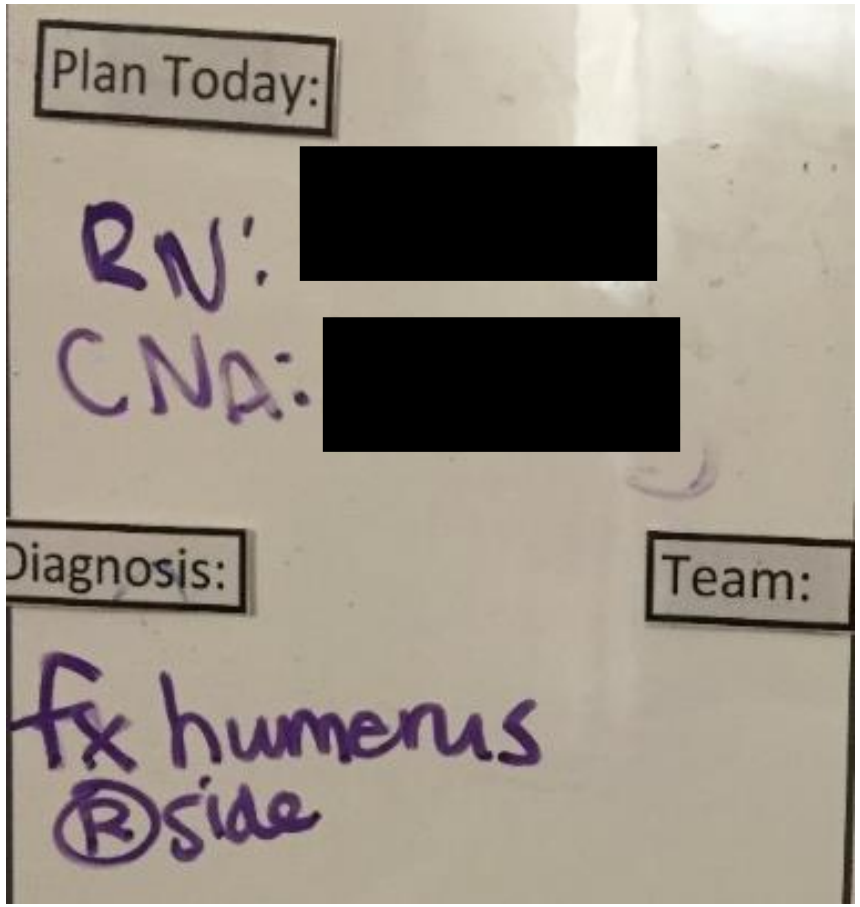


(*AHRQ, 2019; †AHRQ, 2025b)



Hits TV. Grey's Anatomy – Medical Jargon Blitz. YouTube video, 2/26/14 [0:30 excerpt]

Hospital whiteboard jargon study



Among 50 hospitalized adults' whiteboards:

- 100% had at least one undefined jargon term
- 55% of patients had trouble with at least one jargon term

(Coleman & Fondell, In review)

Discharge Instructions - documented in this encounter

Table of Contents for Discharge Instructions

Discharge Instructions

Attachments

Discharge Instructions

9:37 AM PST

Formatting of this note is different from the original.
Images from the original note were not included.

Below are important instructions written by your hospital provider

It was our pleasure being a part of your care team at

You were admitted to the hospital because of:
Rhabdomyolysis which we treated with IVF. Your hospitalization was complicated by the development of acute blood loss anemia and acute decompensated cirrhosis.

After leaving the hospital it is important that you do these things:
Continue engaging with PT
It will be important you continue your lactulose once you leave the hospital. Since we have discontinued your rifaximin, it will be important to follow up with your PCP
Follow up with PCP
In addition to talking about lactulose, please talk with your PCP about resuming your metoprolol (which we have held) as well as management of diabetes
Follow up with Palliative Care team

Please contact or return to the Emergency Department if you have any of these signs or symptoms:
New fevers
Any chest pain especially if accompanied by shortness of breath
Light headedness or dizziness
Bloody or dark tarry stools
New or worsening abdominal pain especially if accompanied by any fever or nausea or vomiting
Worsening weakness or any fall.

Please see the rest of this document for follow up appointments and medication changes

Indication of the number of years of formal education that a person requires in order to easily understand the text on the first reading	
Gunning Fog index:	12.56
Approximate representation of the U.S. grade level needed to comprehend the text:	
Coleman Liau index:	11.67
Flesch Kincaid Grade level:	10.22
ARI (Automated Readability Index)	8.6.3
SMOG:	12.33

Online-Utility.org. Tests Document Readability – Readability Calculator. https://www.online-utility.org/english/readability_test_and_improve.jsp

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(*Hospital Consumer Assessment of Healthcare Providers and Systems)

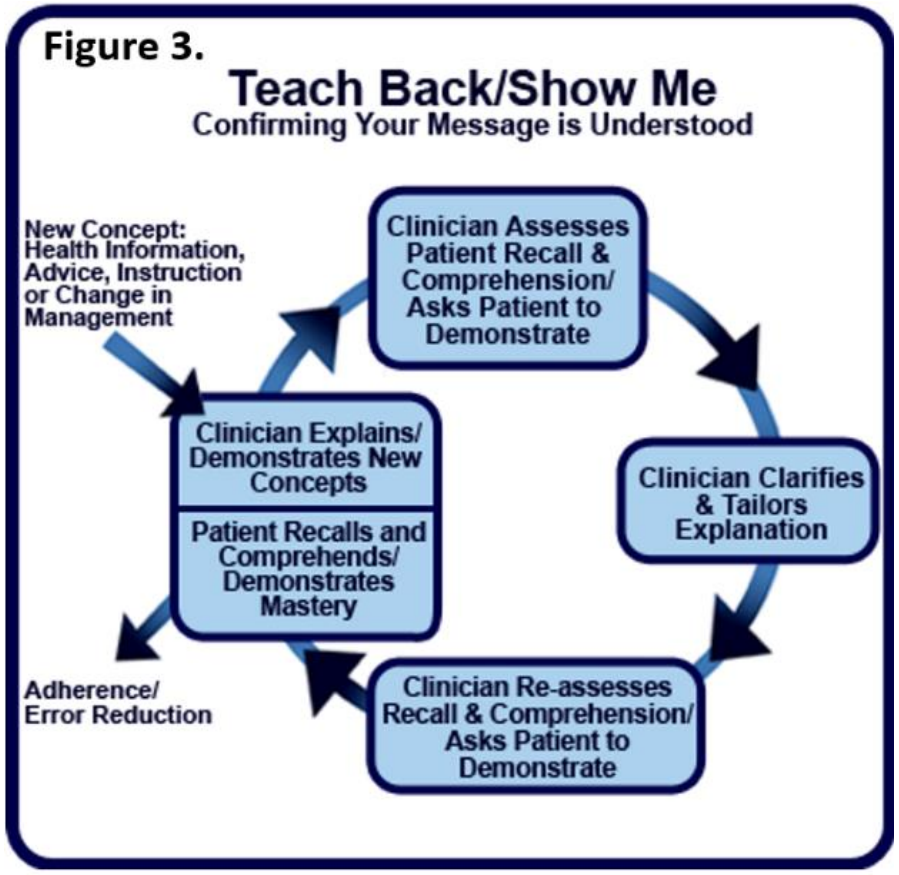
Reliance on patients' self-reported understanding…

Prevents recognition of a need for clearer communication by:

- Health care professionals
- Health professions educators
- Health system administrators
- Payers (e.g., Medicare)
- Accrediting agencies (e.g., The Joint Commission)

Teach-back

Teach-back



Source: Schillinger D, et al. (2003). Closing the loop. Physician communication with diabetic patients who have low health literacy. *Arch Intern Med,*163:83-90

- An open-ended approach that requires demonstration of understanding.
- A check on how clear *we* have been.
- The key is to make it about *you.*
- Variety of approaches:

- *"I want to make sure I've explained things clearly. In your own words, please tell me back the plan."*
- *"How would you explain this to your partner?"*
- *"Show me how you use this inhaler."*

(Schillinger et al, 2003)

Teach-back

- A top safety practice.[1]
- A top-rated clear communication practice.[7]
- A *Healthy People 2030* goal.[8]

- Takes ~1 minute; same as usual care.[2,3]
- May save time at emergency department discharge.[2]
- Generally acceptable to patients.[13]

Associated with:

↑ Knowledge, understanding, retention, recall[2,3,4,11,12]
↑ Adherence to treatment[4,5]
↑ Self-management of diabetes and heart failure[4,12]
↑ Self-efficacy[4]
↑ Control of diabetes[3]
↓ Readmissions by up to 45%[6,9,10,11,12]
↑ Quality of life[11,12]
↑ Satisfaction[12]

([1]NQF, 2003; [2]Mahajan et al, 2020; [3]Schillinger et al, 2003; [4]Ha Dinh et al, 2016; [5]Hirsh et al, 2020; [6]Oh et al, 2023; [7]Coleman et al, 2017; [8]US DHS, nd; [9]Mashhadi et al, 2021; [10]Oh et al, 2021; [11]Talevski et al, 2020; [12]Yen & Leasure, 2019; [13]Samuels-Kalow et al, 2015)

“OHSU's Modified 4 Habits for Patient-Centered Communication” (Coleman & Christian, 2019 [1:09 excerpt])
https://www.youtube.com/watch?v=7KnxVbUIrY4

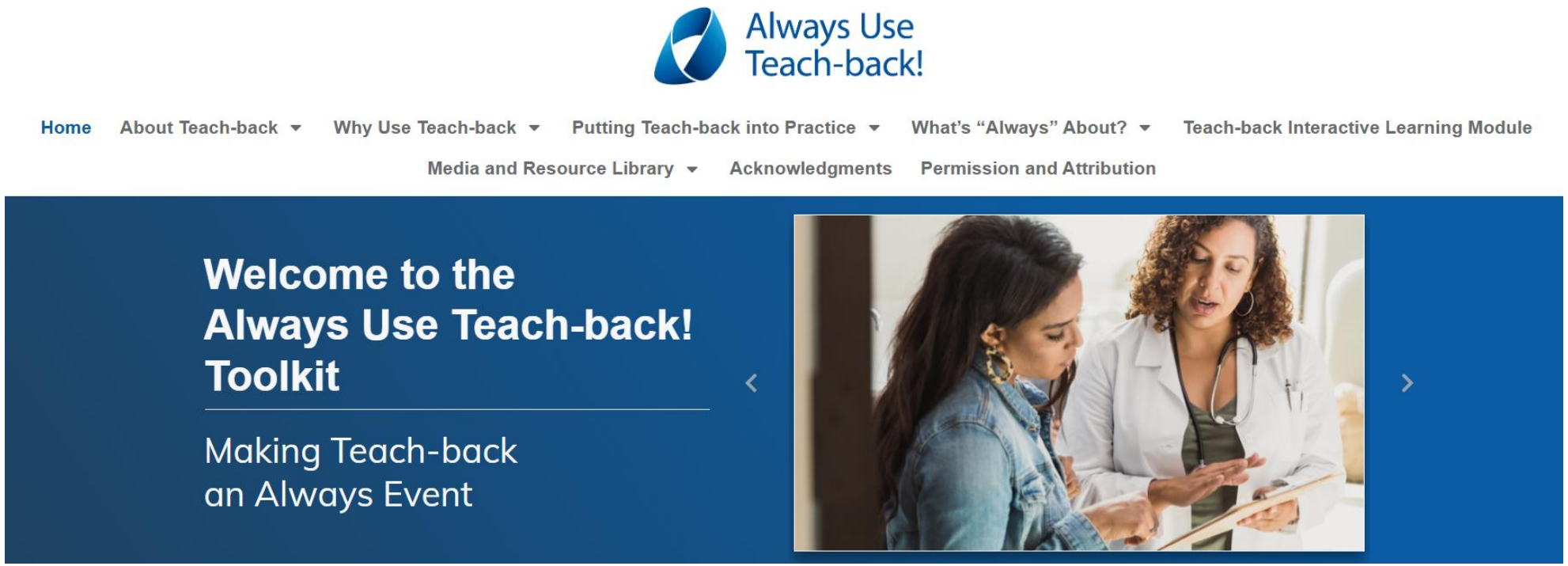
Draft teach-back policy for hospital discharge

- Prior to discharge, a privileged staff member (nurse, nurse practitioner, pharmacist, physician, or physician assistant) will conduct a teach-back with each patient or designated caregiver.

- Teach-back will be used to elicit a demonstrated understanding of the patient's: 1) main problem(s), 2) what to do about it(them), and 3) reason(s) why doing this is important.

- Demonstrated understanding will be documented in the medical record. If the individual is not able to teach-back an acceptably safe understanding of key information, a follow-up plan will be documented.

Learn more



https://teachbacktraining.org/

(Abrams et al, 2024)

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Thank you!

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