UCSF
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# Taking a Deeper Dive: Hearing Loss and Hearing Aid Stigma in the Healthcare - Family Context

Margaret Wallhagen, PhD, GNP-BC, FAAN
Professor, Department of Physiological Nursing

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# Problem

Despite multiple efforts and new technologies, efforts to get *broad sustainable* approaches to promoting communication access in healthcare setting have not been successful.

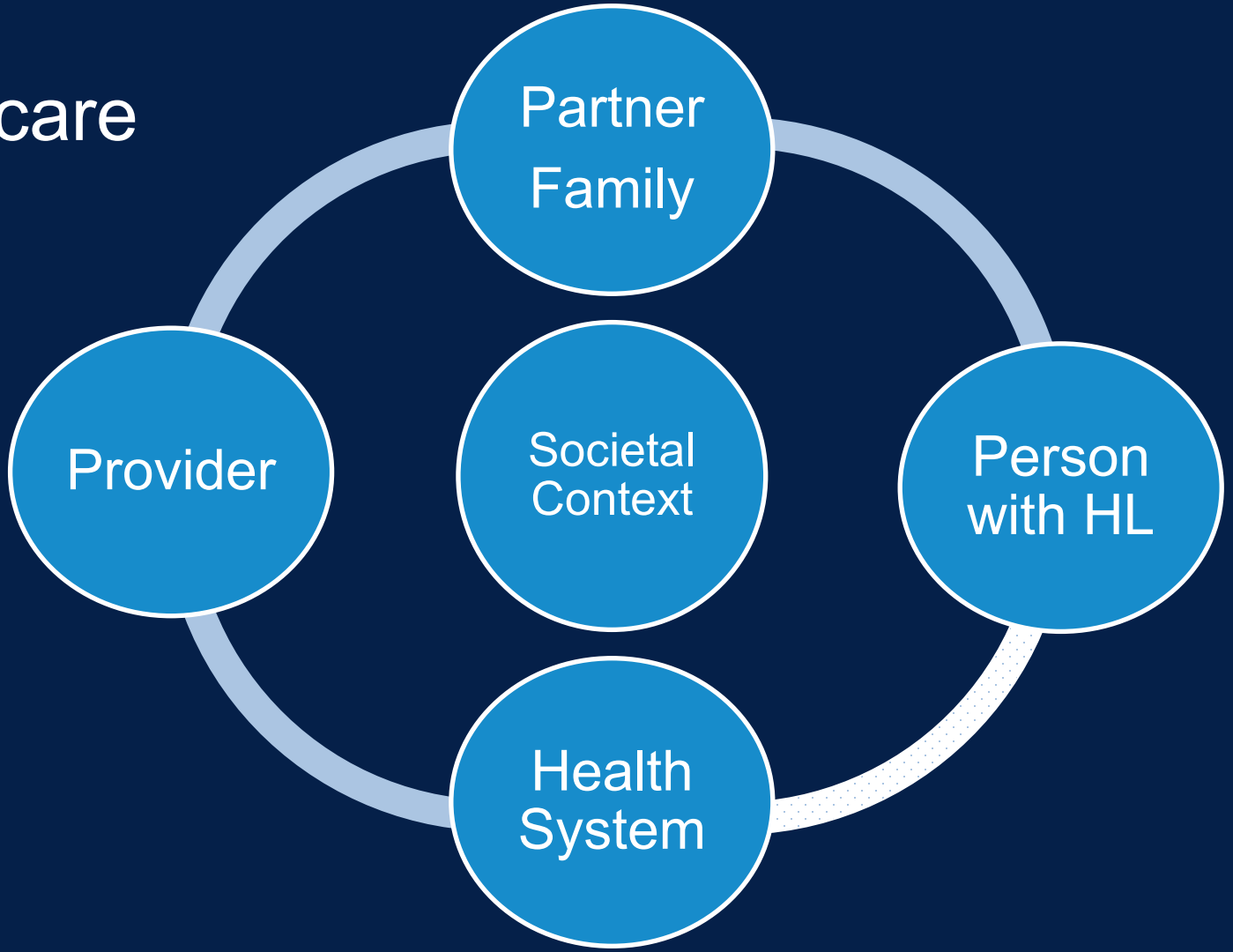
What role does hearing loss and hearing aid stigma play in this lack of progress?

To date this issue has been poorly or understudied

# Objectives

- Discuss stigma in the context of the healthcare system-practitioner-person with hearing loss-family tetrad
- Share manifestations of stigma-ageism biases within the healthcare system as they impact the delivery or receipt of quality, person-centered care
- Discuss healthcare system - practitioner barriers to the integration of sustainable strategies to promote communication access.
- Identify strategies to leverage the age friendly healthcare system and 4Ms “What Matters” framework to achieve the goal of minimizing stigma and integrating communication access across the healthcare system

# Healthcare Tetrad



# Hearing loss impact on receipt of quality palliative care

Manifestations of stigma-ageism bias

# Impact of Hearing loss on Care

- Compromised Symptom Assessment
- Misinterpreting Cognitive Status
- Left Out of Goals of Care Discussions

# Compromised Symptom Assessment

Practitioners noted that their symptom assessment often ended up being limited or not completed.

- “It’s difficult to assess symptoms accurately when the pt has a hearing loss.”

- “I tend to not do a full symptom assessment when confronted with problems in communication.”

# Misinterpreting Cognitive Status

- “[A] patient can be assumed disoriented if not answering questions correctly. It can be very difficult to assess a patient who cannot hear what you are asking them.”
- “Prior to the [erasable communication board], everyone on the team thought he was demented. He wasn’t.”
- “An elderly man whom people assumed had dementia; he did not and felt very belittled.”

# Left Out of Goals of Care Discussions

Palliative care aims to align care with patient preferences.

- “Self-determination in decision-making can be more difficult. They may defer to their family as they can’t hear the options presented.’’
- ‘‘The patient could not hear well, and the caregiver spoke on the [his] behalf despite attempts to communicate directly with the patient.”
- “ The patient was not able to participate fully in decision making …, they thought he was confused and noncompliant.”

# What about Primary Care?

## Never Asked

# Never Asked-Wanting To Know

Not that I recall….because ***I never came in for any issues with my hearing*** and I didn't get my hearing aid from {health system}. I'm thinking of my current person. Probably way back when, 10 years ago before I got a hearing aid, I'm sure we discussed it, because obviously somebody at the {X} Clinic referred me to the hearing department. But that, ***actually, because I initiated it*** because I could tell ***I needed an aid for work*** so I have to say really no….[and] ***I'm not bashful about saying could you please repeat that.***

# No Accommodation

M: I also, unfortunately, have ended up in the ER a few times, because I have some coronary artery issues. I have a couple of stents. And **I'll tell them, you know, I'm deaf in the right ear and there's not a whole lot of attention to it.**

Even in the ER?

M: Yeah, ***even in the ER, yeah***

# Missing Information Without Knowing

….Do you routinely tell them that you have difficulty hearing?

M: ***I do more now,*** because ***I need to hear what they say***. I need to know what points they're trying to make, so yeah, ***it is past the point where, you know, just tolerating it, or letting it slip by,*** **yeah, yeah**.

# Barriers To Advocacy

-So, you always asked for clarification?

P: Yes. If I couldn't hear, I did, yeah. ***I felt funny about it though***. You know, ***you hate to say what did you say?*** But I did, ***because I needed to know.***

--Why did you feel sorry or bad about saying that you needed to have them clarify what they were saying

P: Because, I guess, ***I didn't want people to think I couldn't hear….***It's like there's something the matter with you. ***What's wrong with you? You can't hear?***

# To Advocate

To Speak Out, Speak For, Recommend, Argue

In Support Of Cause Or Approach

# Charlotte Hyde: Pros & cons of self-advocacy

- *Open*, individuals that are happy to talk about their deafness/disability and access
- *Anxious*, those who are not comfortable discussing their deafness/disability and access;
- *Unaware*, those who do not know they are deaf/disabled.

https://limpingchicken.com/2021/07/22/charlotte-hyde-the-pros-and-cons-of-self-advocacy/

# Charlotte Hyde: Pros & Cons of Self-Advocacy

"*This constant self-advocacy can lead to burnout. I can begin to feel anxious again about telling people I am deaf or asking someone to communicate with me in a different way. I end up forgetting parts of my usual script, leading to further mop-up conversations in the future.*"

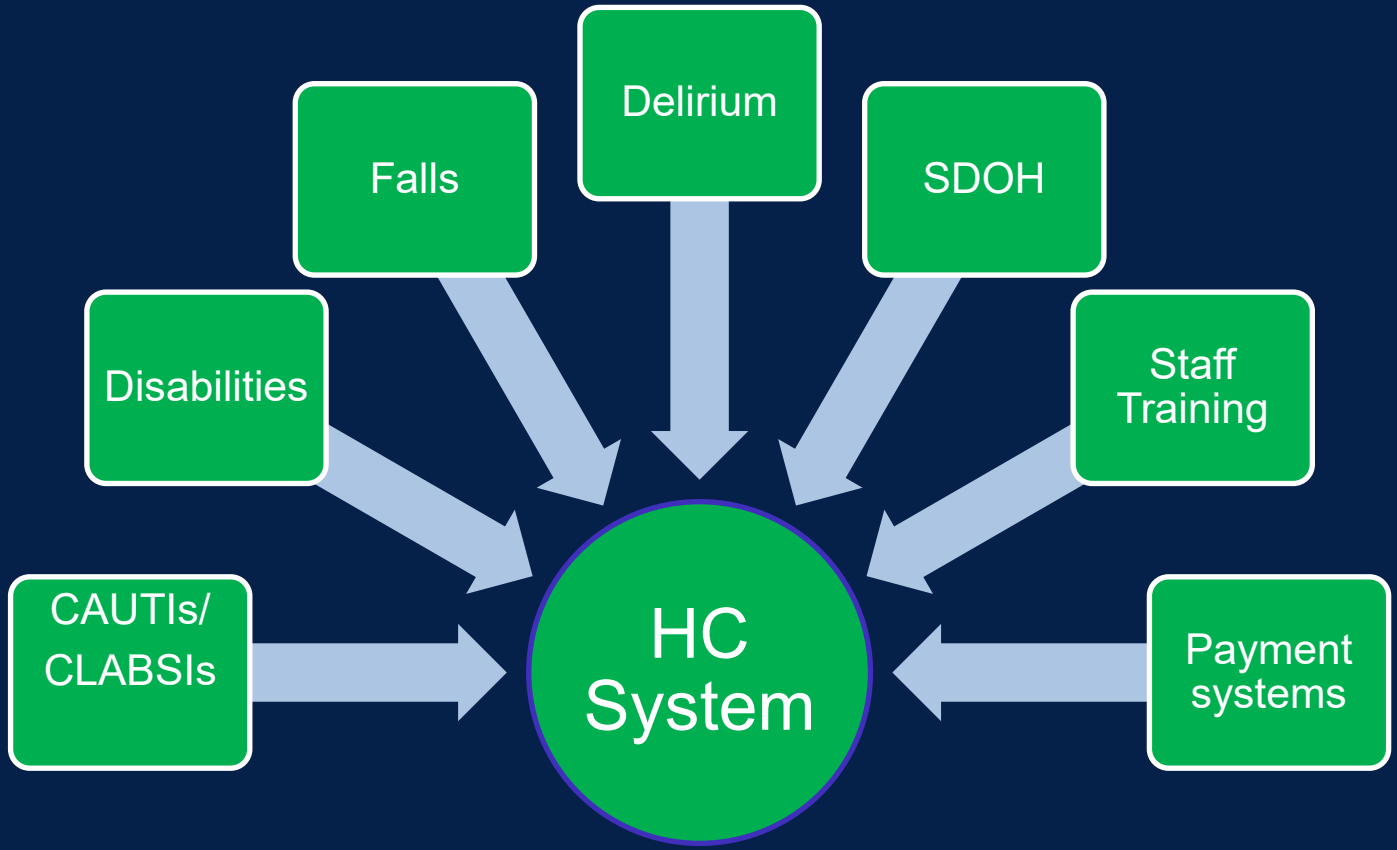
*"Hearing people do need to be reminded. They start out well but soon forget that I need to see their lips. They speak clearly for the first few sentences, then taper off into a mumble. It is a perpetual internal battle between 'am I making too big a deal of this?' and 'I deserve access'".*

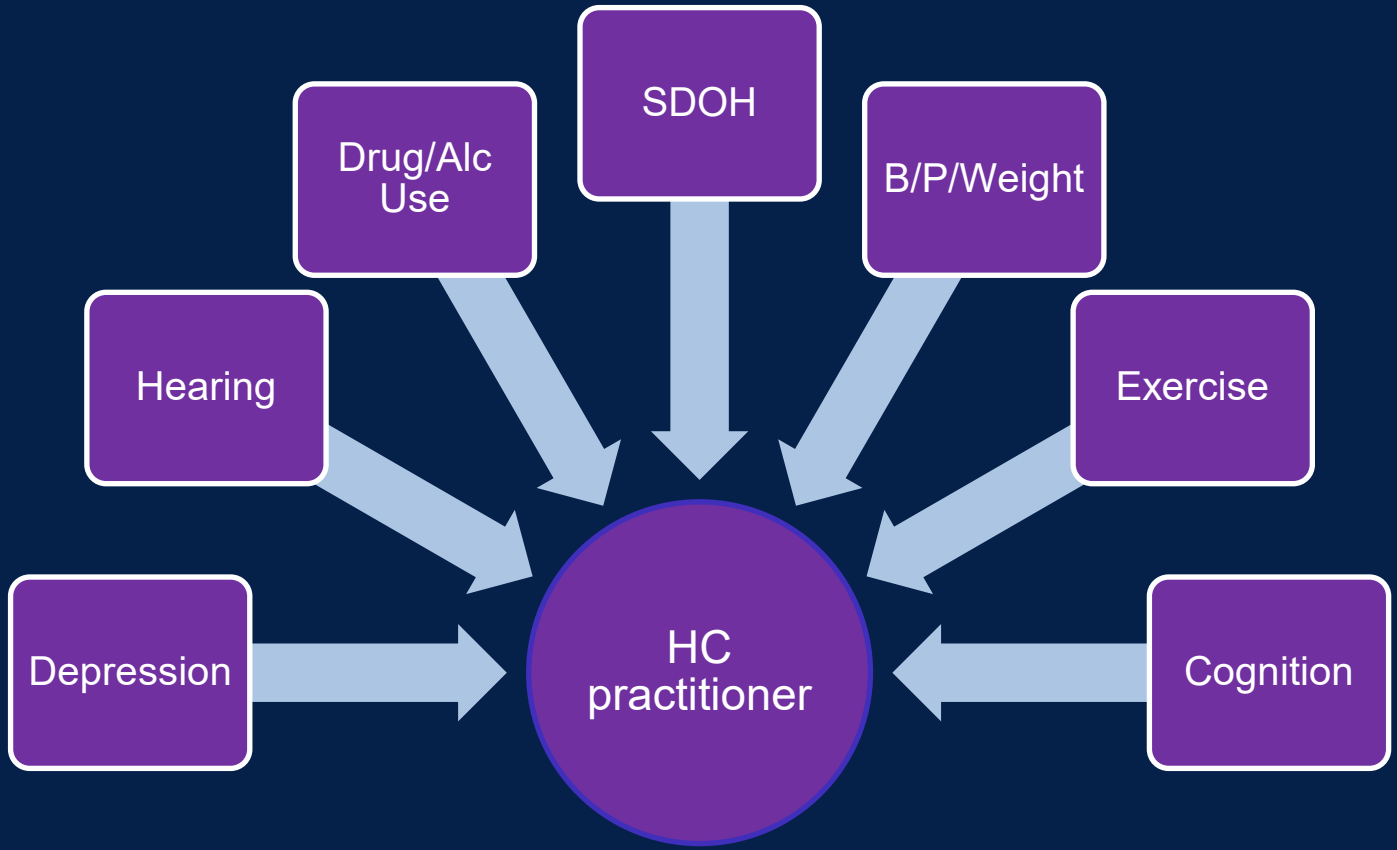
# Shared Advocacy

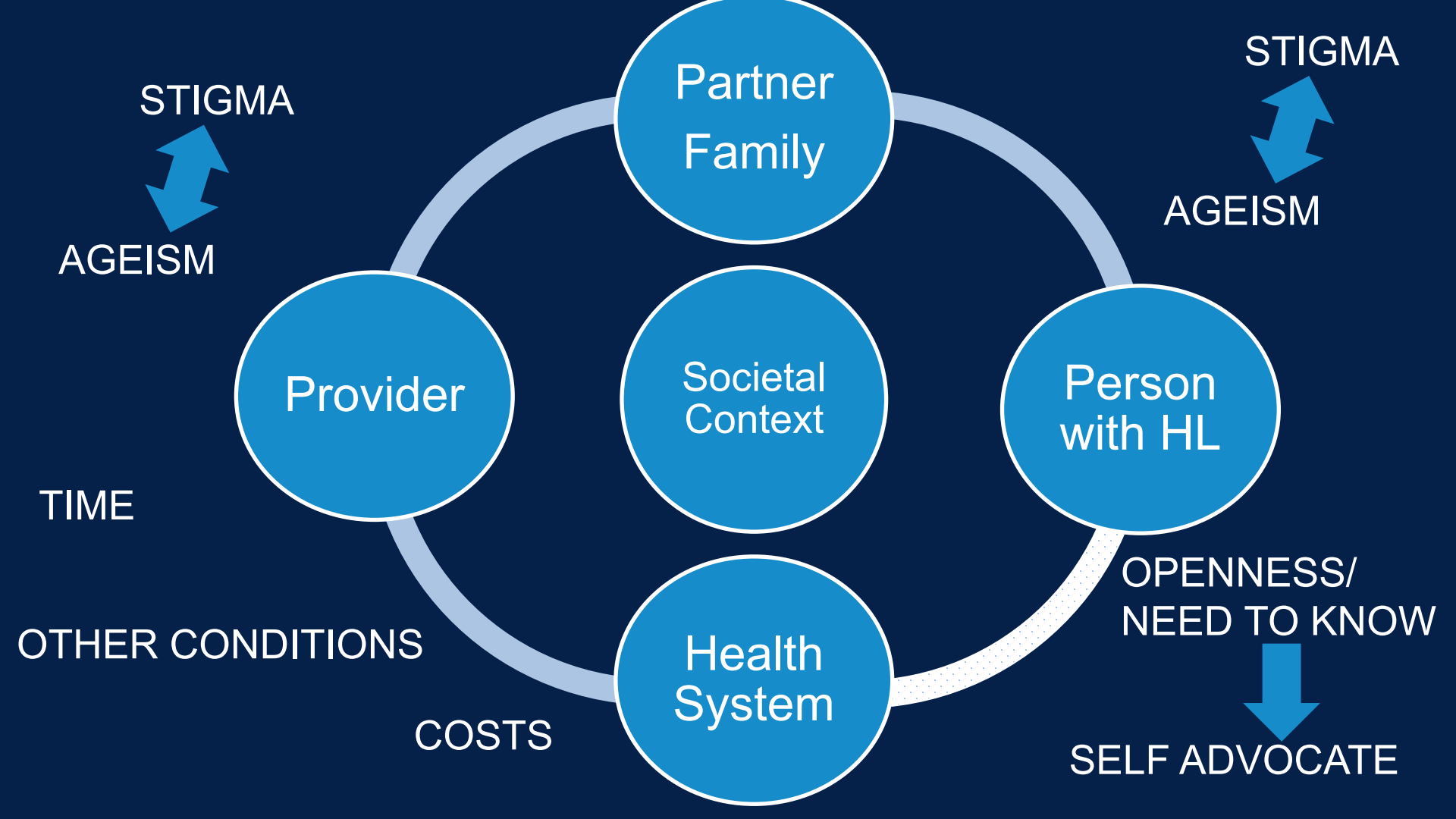
Patient/Family ⟷ Practitioner

Power Differential

Competing Demands


Delirium
Falls
SDOH
Disabilities
Staff Training
CAUTIs/ CLABSIs
HC System
Payment systems


SDOH
Drug/Alc Use
B/P/Weight
Hearing
Exercise
Depression
HC practitioner
Cognition


STIGMA
AGEISM
Partner
Family
STIGMA
AGEISM
Provider
Societal
Context
Person
with HL
TIME
OPENNESS/
NEED TO KNOW
OTHER CONDITIONS
Health
System
COSTS
SELF ADVOCATE

# A Way Forward?

## Age Friendly Health System

# Age-Friendly Health Systems

Initiative of The John A Hartford Foundation and the Institute for Healthcare Improvement (IHI), in partnership with the American Hospital Association and Catholic Health Association with goal to address unmet health care needs of older adults


An initiative of The John A. Hartford Foundation and the Institute for Healthcare Improvement (IHI) in partnership with the American Hospital Association (AHA) and the Catholic Health Association of the United States (CHA).

4Ms Framework of an Age-Friendly Health System (with descriptions)

## What Matters

Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

## Medication

If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

## Mentation

Prevent, identify, treat, and manage dementia, depression, and delirium across care.

## Mobility

Ensure that older adults move safely every day in order to maintain function and do What Matters.

# Hearing is Essential in a AF Health System

- **What Matters**:
  - To communicate goals of care & personal values
- **Medication**:
  - To understand regimen
- **Mentation**:
  - HL affects cognition and is a risk factor for delirium
- **Mobility**:
  - HL is a risk factor for falls

# Feasible?

## CMS Age Friendly Hospital Measures

Hospitals participating in Medicare's Hospital Inpatient Quality Reporting Program have have protocols are in place to:

1) Elicit patient health care goals,

2) Responsibly manage medications,

3) Implement frailty screening and intervention

4) Assess social vulnerability

5) Designate age-friendly leadership.

# TABLE IX.C-1. THE AGE FRIENDLY HOSPITAL MEASURE'S FIVE DOMAIN ATTESTATIONS

| Attestation Domains | Attestation Statements: Attest "yes" or "no" to each element.<br>(Note: Affirmative attestation of all elements within a domain would be required for the hospital or health system to receive a point for that domain) |
|---|---|
| **Domain 1: Eliciting Patient Healthcare Goals**<br>This domain focuses on obtaining patient's health related goals and treatment preferences which will inform shared decision making and goal concordant care. | **(A)** Established protocols are in place to ensure patient goals related to healthcare (health goals, treatment goals, living wills, identification of healthcare proxies, advance care planning) are obtained/reviewed and documented in the medical record. These goals are updated before major procedures and upon significant changes in clinical status. |
| **Domain 2: Responsible Medication Management**<br>This domain aims to optimize medication management through monitoring of the pharmacological record for drugs that may be considered inappropriate in older adults due to increased risk of harm. | **(A)** Medications are reviewed for the purpose of identifying potentially inappropriate medications (PIMs) for older adults as defined by standard evidence-based guidelines, criteria, or protocols. Review should be undertaken upon admission, before major procedures, and/or upon significant changes in clinical status. Once identified, PIMS should be considered for discontinuation, and/or dose adjustment as indicated. |
| **Domain 3: Frailty Screening and Intervention**<br>This domain aims to screen patients for geriatric issues related to frailty including cognitive impairment/delirium, physical function/mobility, and malnutrition for the purpose of early detection and intervention where appropriate. | **(A)** Patients are screened for risks regarding mentation, mobility, and malnutrition using validated instruments ideally upon admission, before major procedures, and/or upon significant changes in clinical status.<br>**(B)** Positive screens result in management plans including but not limited to minimizing delirium risks, encouraging early mobility, and implementing nutrition plans where appropriate. These plans should be included in discharge instructions and communicated to post-discharge facilities.<br>**(C)** Data are collected on the rate of falls, decubitus ulcers, and 30-day readmission for patients > 65. These data are stratified by demographic and/or social factors.<br>**(D)** Protocols exist to reduce the risk of emergency department delirium by reducing length of emergency department stay with a goal of transferring a targeted percentage of older patients out of the emergency department within 8 hours of arrival and/or within 3 hours of the decision to admit. |
| **Domain 4: Social Vulnerability**<br>This domain seeks to ensure that hospitals recognize the importance of social vulnerability screening of older adults and have systems in place to ensure that social issues are identified and addressed as part of the care plan. | **(A)** Older adults are screened for geriatric specific social vulnerability including social isolation, economic insecurity, limited access to healthcare, caregiver stress, and elder abuse to identify those who may benefit from care plan modification. The assessments are performed on admission and again prior to discharge.<br>**(B)** Positive screens for social vulnerability (including those that identify patients at risk of mistreatment) are addressed through intervention strategies. These strategies should include appropriate referrals and resources for patients upon discharge. |
| **Domain 5: Age-Friendly Care Leadership**<br>This domain seeks to ensure consistent quality of care for older adults through the identification of an age friendly champion and/or interprofessional committee tasked with ensuring compliance with all components of this measure. | **(A)** Our hospital designates a point person and/or interprofessional committee to specifically ensure age friendly care issues are prioritized, including those within this measure. This individual or committee oversees such things as quality related to older patients, identifies opportunities to provide education to staff, and updates hospital leadership on needs related to providing age friendly care.<br>**(B)** Our hospital compiles quality data related to the Age Friendly Hospital measure. These data are stratified by demographic and/or social factors and should be used to drive improvement cycles. |

# Conclusions And Future Directions

- Persons with hearing loss still need to self-advocate in the healthcare environment but should not bear the full burden of having their needs met.
- Leveraging the Age Friendly Health Systems and new CMS Age Friendly Hospital Measures Policy may facilitate integration of hearing assessments into the normal workflow across all aspects of the health system
- Research is needed on strategies to leverage the age-friendly health systems initiative to promote incorporation of hearing assessment.
- Integration can minimize misunderstandings and mitigate the stigma and negative impact of hearing loss
- Research is needed to better understand stigma in the context of the healthcare system and how practitioners understand the impact of hearing loss on older adults and their partners.


Thank You!