# Understanding and addressing stigma associated with low health literacy

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THE UNIVERSITY OF NORTH TEXAS

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# Agenda

> Understanding Health Literacy

> Stigma in a Health Care Context

> Patients' Perceived Stigma

# Definition

What is health literacy?

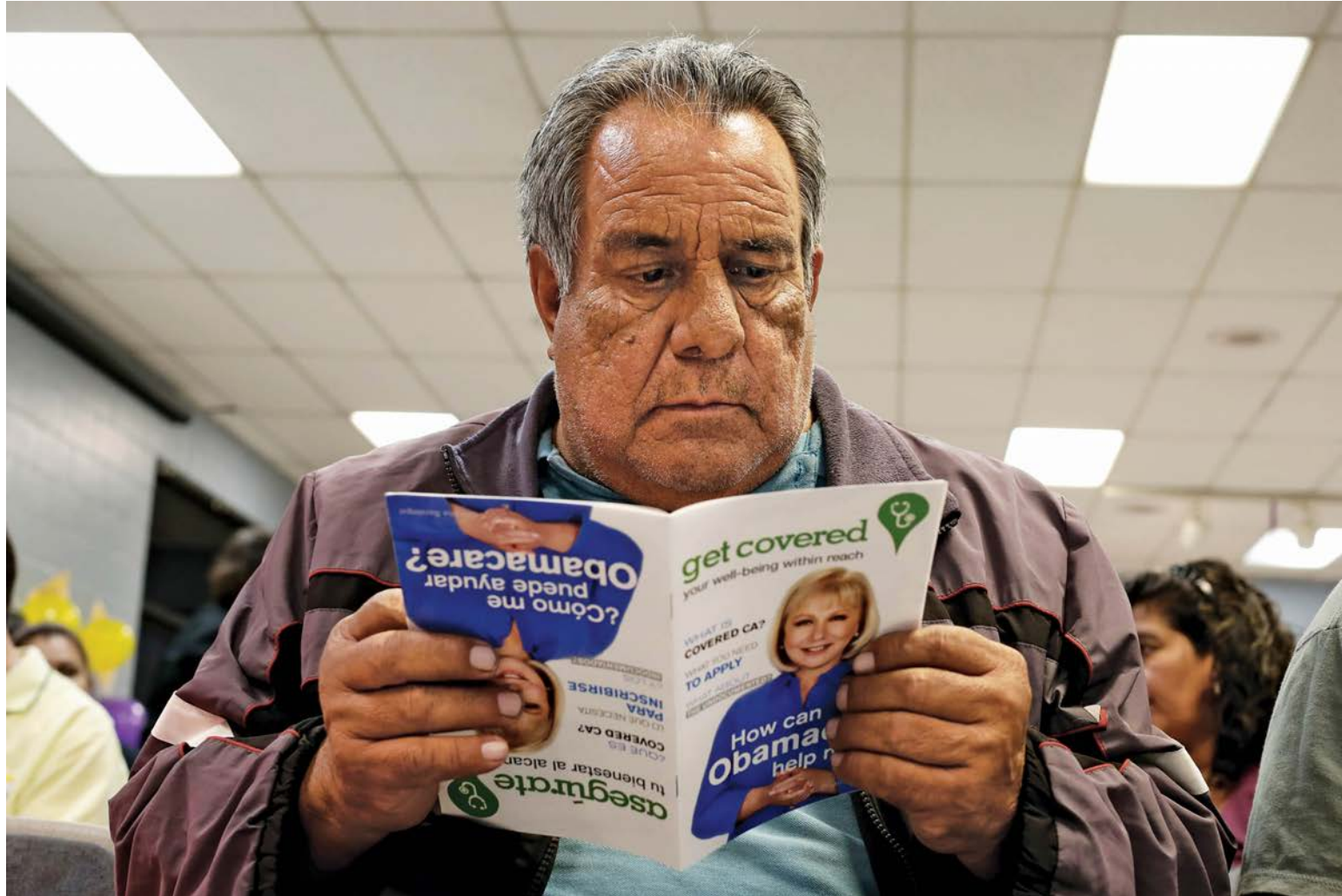# Definition

What is health literacy?

"the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"

Originally developed for Ratzan SC, Parker RM. 2000. Introduction. In National Library of Medicine Current Bibliographies in Medicine: Health Literacy. Selden CR, Zorn M, Ratzan SC, Parker RM, Editors. NLM Pub. No. CBM 2000-1. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services.

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"the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions."

Berkman, N.D., Davis, T.C., McCormack, L. (2010). Health literacy: What is it? Journal of Health Communication, Suppl 2, 9-19.
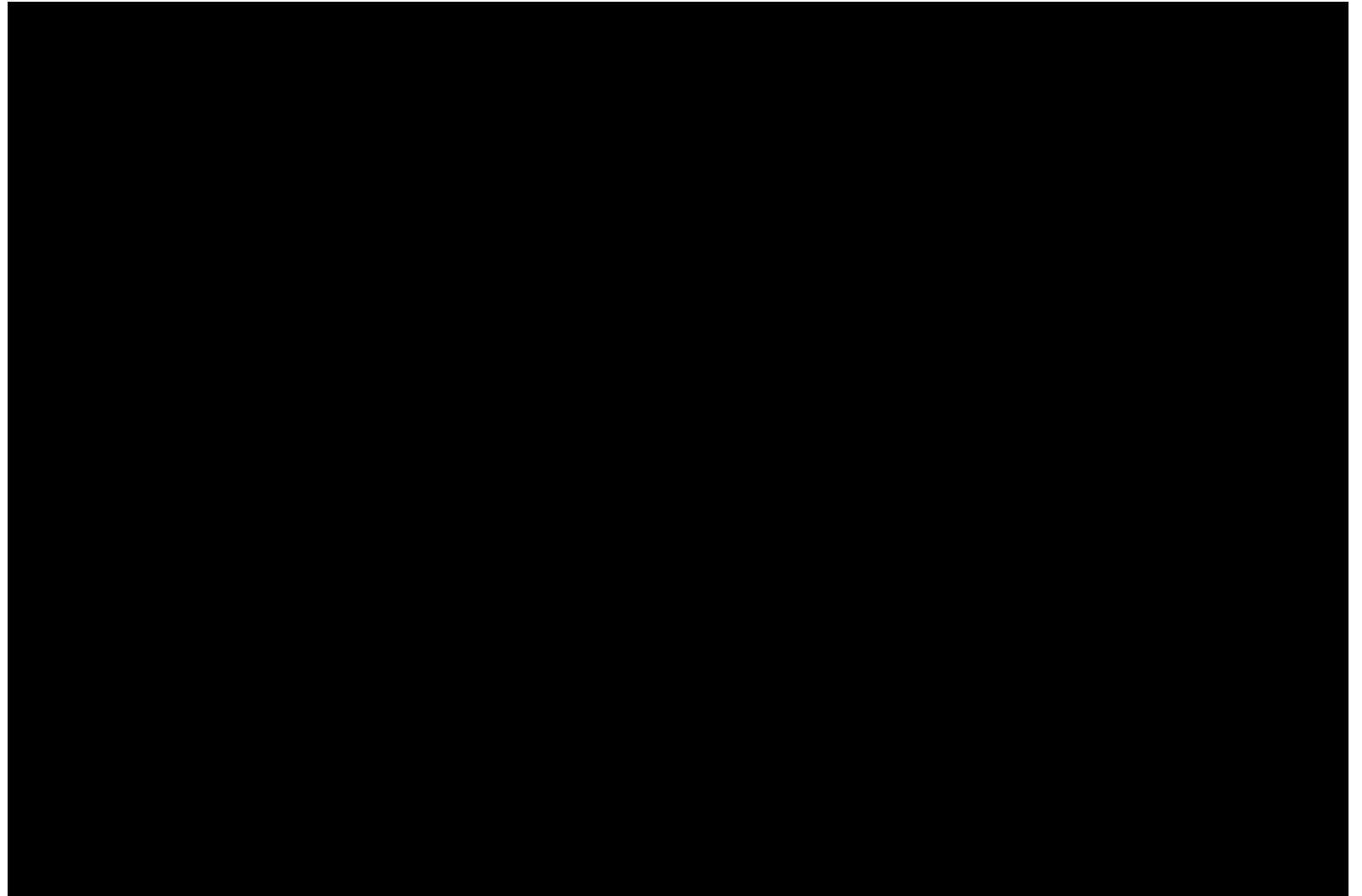
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# Definition

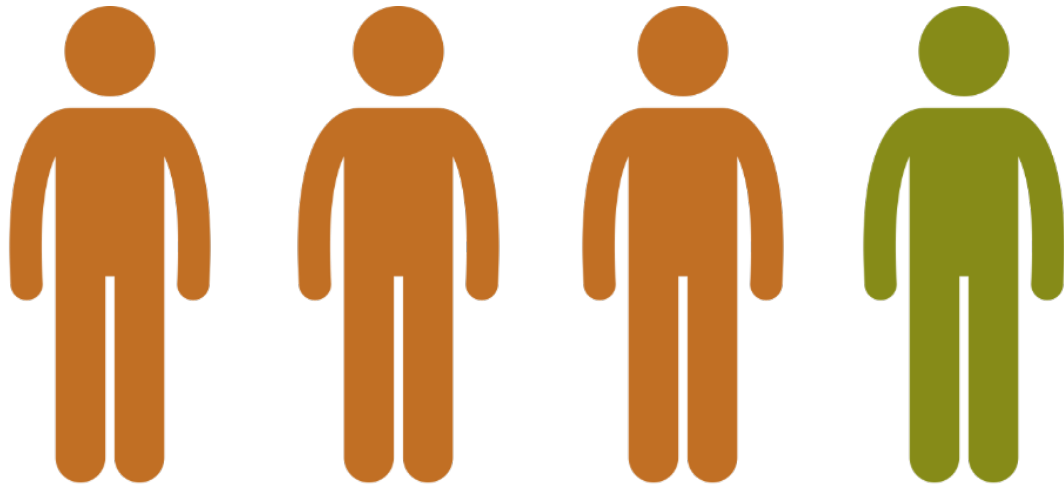What is health literacy?

# Prevalence

Limited large-scale studies

# Prevalence

Limited large-scale studies



Paasche-Orlow, M.K., Parker, R.M., Gazmararian, J.A., Nielsen-Bohlman, L.T., Rudd, R.R. (2005). The prevalence of limited health literacy. J Gen Intern Med, 20(2), 175-84.
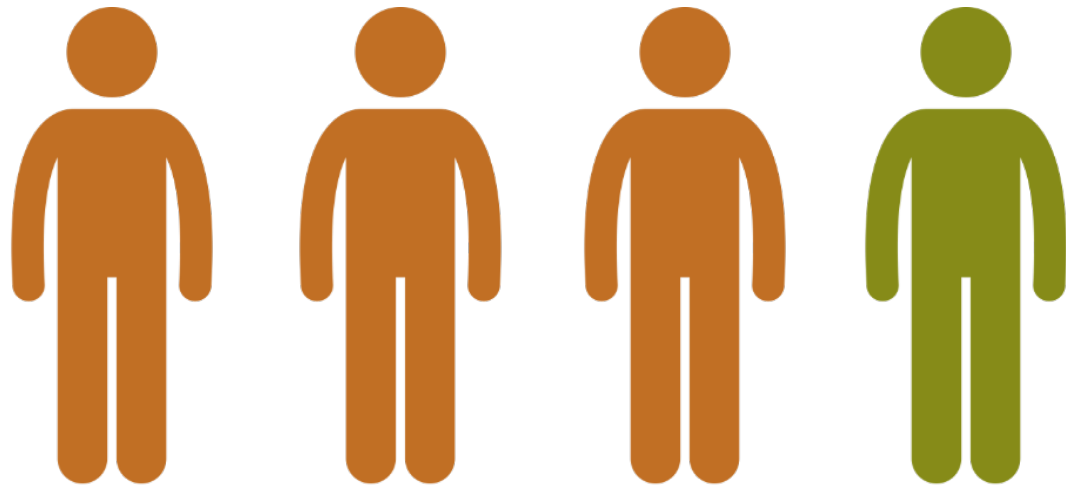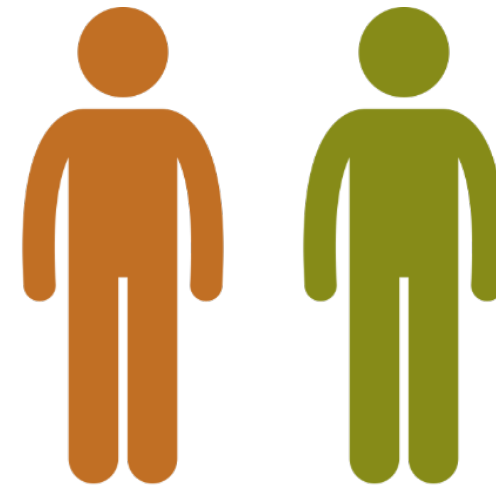
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# Outcomes

Widespread challenges

# Outcomes

Widespread challenges

Decreased Comprehension of Health Concepts

# Outcomes

Widespread challenges
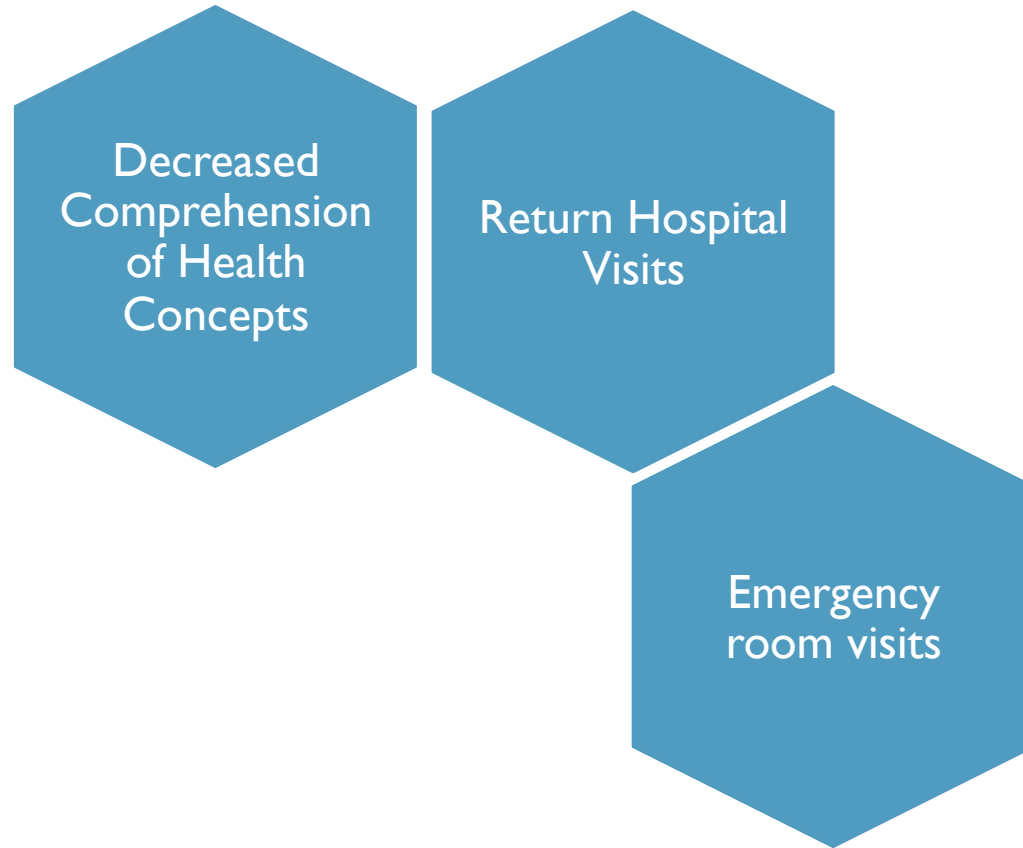
Decreased Comprehension of Health Concepts

Return Hospital Visits

# Outcomes
Widespread challenges
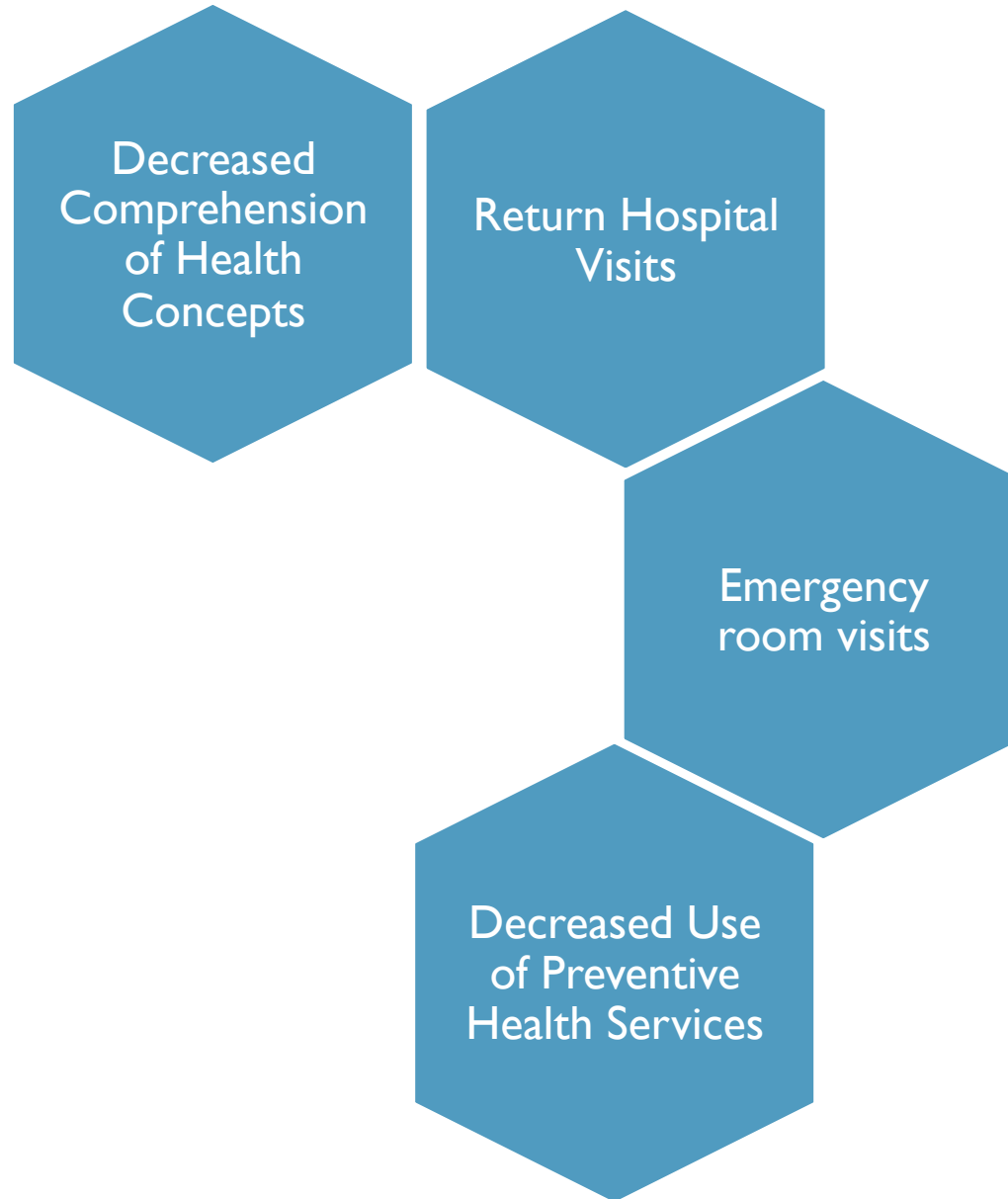
Decreased Comprehension of Health Concepts

Return Hospital Visits

Emergency room visits

# Outcomes

Widespread challenges

Decreased Comprehension of Health Concepts

Return Hospital Visits

Emergency room visits

Decreased Use of Preventive Health Services

# Outcomes
Widespread challenges

# Outcomes

Widespread challenges



Decreased Comprehension of Health Concepts

Return Hospital Visits

Non-Adherence to Instructions

Emergency room visits

Fewer Health Screenings

Decreased Use of Preventive Health Services
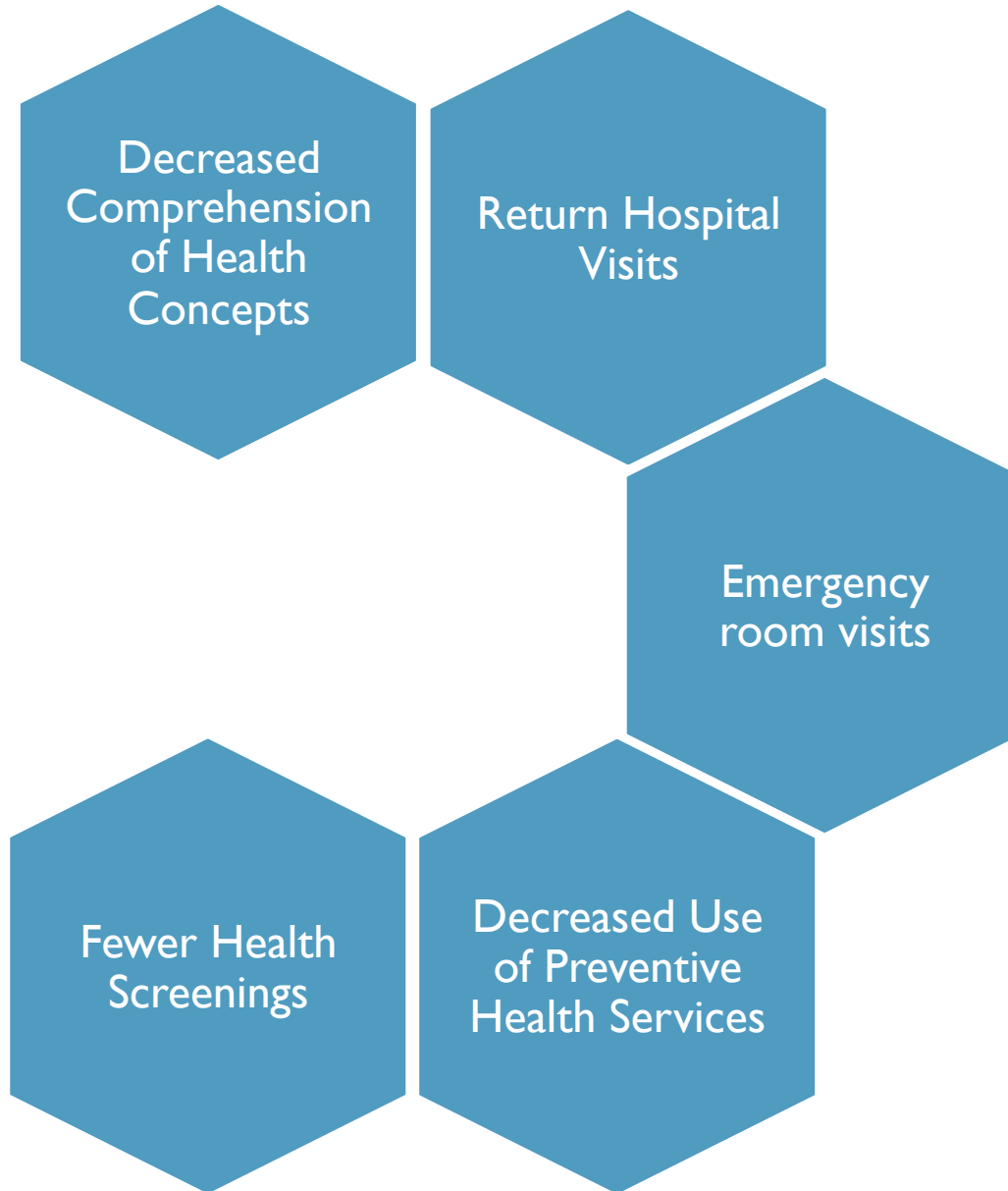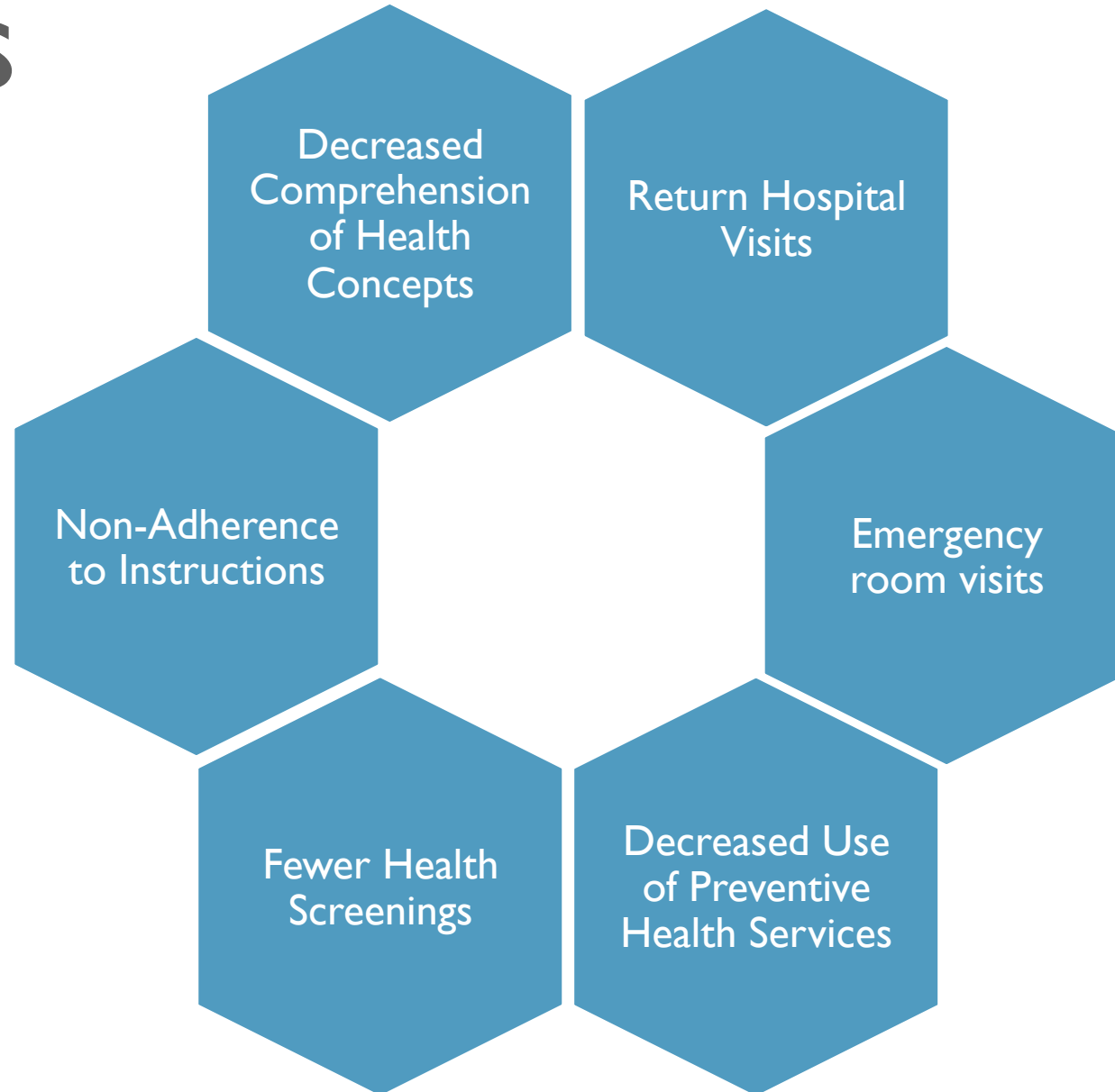
# Outcomes

Widespread challenges

# Existing Programs

# Existing Programs

Identifying Challenges

Patient Education

Communication Strategies

# Stigma

A call for research

# Stigma
A call for research

Stigma can be:

- Enacted by others

- Perceived by self

# Stigma

A call for research



Situation:
Salience of stigma
Threat of discovery
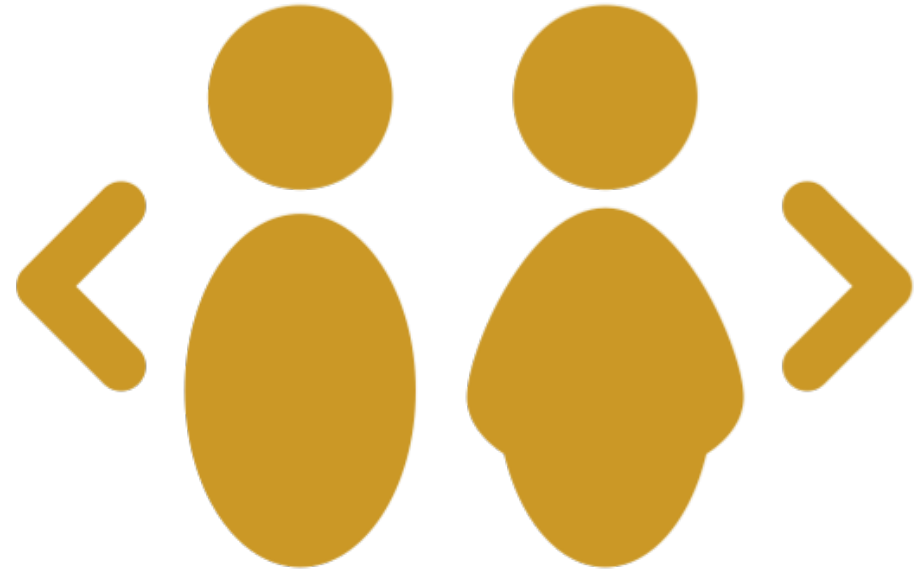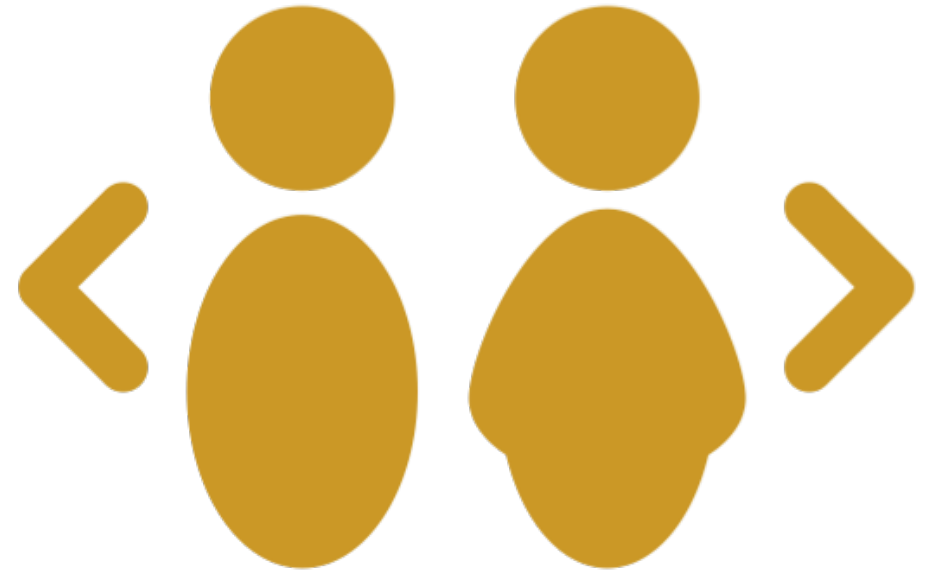Consequences of discovery

Cognitive Implications:
Preoccupation
Vigilance
Suspiciousness

Affective Implications:
Anxiety
Depression
Hostility
Demoralization
Guilt
Shame

Behavioral Implications:
Impression management
Social avoidance and isolation
Increased importance of feedback
Impaired close relationship functioning

Disclosure

Feedback

Self-Evaluative Implications:
Identity ambivalence          Lack of access to group-based self-protective attributions
Negative view of self         Diminished self-efficacy

Pachankis, J.E. (2007). The psychological implications of concealing a stigma: A cognitive-affective-behavioral model. Psychological Bulletin, 133 (2), 328-45.

# Stigma
Exacerbating effects

??????

Interpreting
Test Results

Asking
Questions

Completing
Forms

Reading
Health Texts

# Stigma
Non-disclosure

# Stigma

Who to tell?

**Table 3.** Patient perceptions of shame associated with disclosure of literacy ability
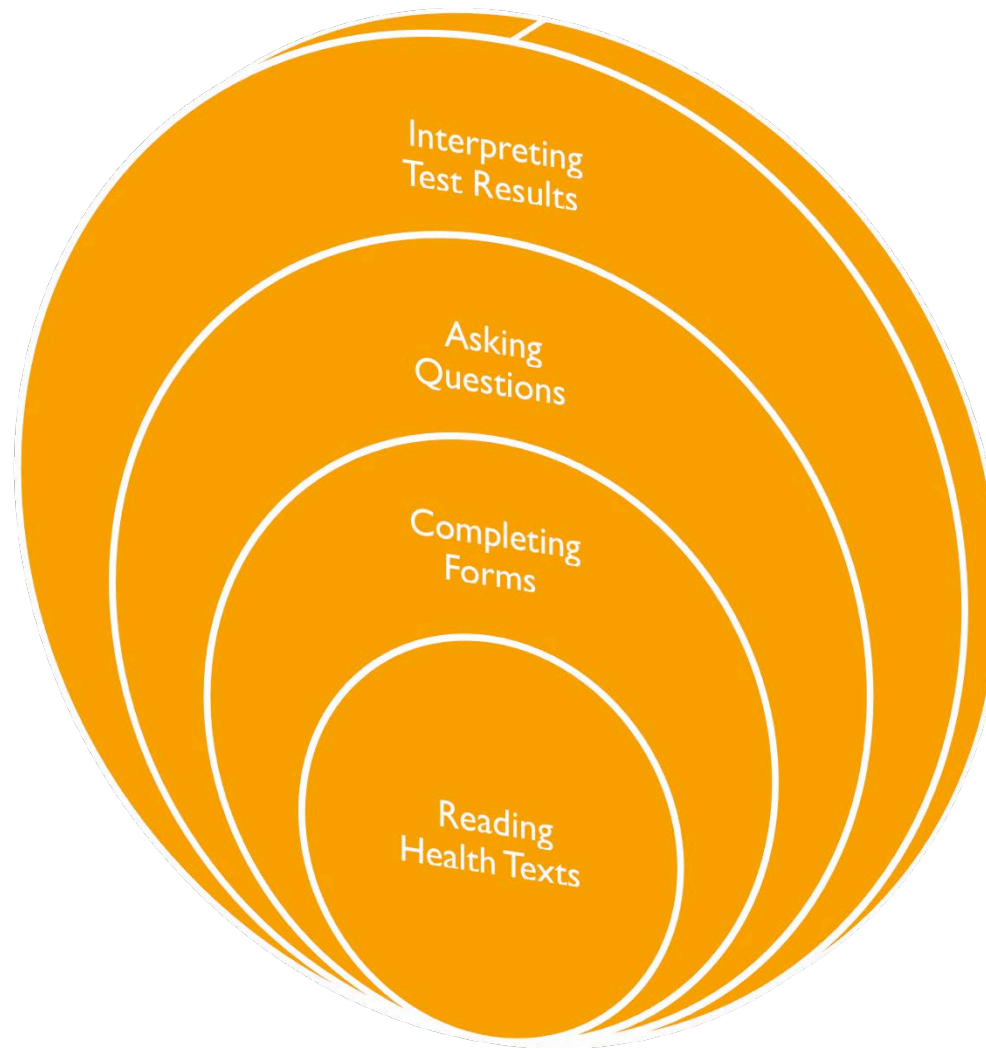
| Disclosure | REALM Score | | | P Value |
|---|---|---|---|---|
| | Level I ≤3rd grade (n = 66) | Level II 4th–6th grade (n = 78) | Level III 7th–8th grade (n = 79) | |
| Doctor | | | | |
| Helpful if doctor knows | 93.9 | 96.0 | 94.8 | 0.78 |
| Feel ashamed if doctor knows | 36.4 | 24.4 | 16.7 | 0.03 |
| Nurse | | | | |
| Helpful if nurse knows | 95.5 | 92.1 | 92.1 | 0.26 |
| Feel ashamed if nurse knows | 33.8 | 21.9 | 15.5 | 0.05 |
| Clerk | | | | |
| Helpful if clerk knows | 93.7 | 91.9 | 84.2 | 0.28 |
| Feel ashamed if clerk knows | 34.4 | 20.5 | 13.0 | 0.08 |
| Ashamed if documented in chart | 35.7 | 19.7 | 14.1 | 0.03 |
| Ashamed if documented on card | 36.9 | 22.1 | 20.6 | 0.39 |
| Refuses to have a card | 9.2 | 13.0 | 16.7 | 0.42 |

Wolf, M.S., Williams, M.V., Parker, R.M., Parikh, N.S., Nowlan, A.W., & Baker, D. W. (2007). Patients' Shame and Attitudes Toward Discussing the Results of Literacy Screening, Journal of Health Communication, 12:8, 721-732,

# Stigma

A call for research

# Stigma
## A call for research

Mackert, M., Donovan, E.E., Mabry, A., Guadagno, M., & Stout, P.A. (2014). Stigma and health literacy: An agenda for advancing research and practice. American Journal of Health Behavior, 38(5), 690-698.

Pescosolido BA, Martin JK, Lang A, Olafsdottir S. Rethinking theoretical approaches to stigma: a Framework Integrating Normative Influences on Stigma (FINIS). Soc Sci Med. 2008;67:431-440.



Figure 1
Framework Integrating Normative Influence on Stigma (FINIS)
in Pescosolido et al (2008)

## *Research Question 1:*

How does participants' self-reported health literacy compare

to their measured health literacy?

Mackert, M., Mabry-Flynn, A., Champlin, S., Donovan, E.E., & Pounders, K.

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## Research Question 3:

How do demographic characteristics of a person with lower

health literacy influence stigmatized perceptions?

Mackert, M., Mabry-Flynn, A., Champlin, S., Donovan, E.E., & Pounders, K.

# Health Literacy
Newest Vital Sign – Objective Measure

**Nutrition Facts**

| | |
|---|---|
| Serving Size | ½ cup |
| Servings per container | 4 |

Amount per serving

| | | | |
|---|---|---|---|
| Calories | 250 | Fat Cal | 120 |

| | %DV |
|---|---|
| **Total Fat** 13g | 20% |
| Sat Fat 9g | 40% |
| **Cholesterol** 28mg | 12% |
| **Sodium** 55mg | 2% |
| **Total Carbohydrate** 30g | 12% |
| Dietary Fiber 2g | |
| Sugars 23g | |
| **Protein** 4g | 8% |

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

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**READ TO SUBJECT:**
This information is on the back of a container of a pint of ice cream.

| | | ANSWER CORRECT? |
|---|---|---|
| | | yes / no |

1. If you eat the entire container, how many calories will you eat?
   *Answer: 1,000 is the only correct answer*

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?
   *Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl?"*

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?
   *Answer: 33 is the only correct answer*

4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?
   *Answer: 10% is the only correct answer*

**READ TO SUBJECT:**
Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?
   *Answer: No*

6. (Ask only if the patient responds "no" to question 5): Why not?
   *Answer: Because it has peanut oil.*

Number of correct answers: _____

Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., … Hale, F. A. (2005). Quick Assessment of Literacy in Primary Care: The Newest Vital Sign. *Annals of Family Medicine*, *3*(6), 514–522. http://doi.org/10.1370/afm.405

# Health Literacy

Single Item Measure – Self-Reported

"How confident are you filling out medical forms by yourself?"

(Not at all, A little bit, Somewhat, Quite a bit, Extremely)

Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. Family Medicine, 36, 588-594.

Chew, L. D., Giffin, J. M., Partin, M. R., Noorbaloochi, S., Grill, J. P, Snyder, A., . . . VanRyn, M. (2008). Validation of Screening Questions for Limited Health Literacy in a Large VA Outpatient Population. Journal of General Internal Medicine, 23(5), 561-566.

# Stigma

Vignettes

# Stigma
Vignettes

## Vignette 1

Mr. S (Ms. S) is a 33-year old White (Hispanic/African American) father (mother) of one. He* has health insurance through Blue Cross/Blue Shield through his employer (Medicare/Medicaid). His daughter had an ear infection. When he picked up her medicine from the pharmacy, he was told to give her one tablespoon twice a day. The pharmacist asked him if he had any questions, and he did not. He thought this was easy and didn't feel like he should have any questions. When he got home, he poured one tablespoon of medicine into her ear – leading to a trip to the emergency room. The doctor at the emergency room could not believe Mr. S. poured medicine into his daughter's ear, but Mr. S. explains that he thought medicine should go where the problem was.

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### Vignette 2

Mr. S (Ms. S) is a 72-year old White (Hispanic/African American) man (woman). He* has Blue Cross/Blue Shield health insurance through his employer (Medicare/Medicaid). He has high blood pressure and high cholesterol. He is on several medications to manage these conditions, but he does not always take his medicine correctly. Sometimes he takes too many pills in a day, sometimes he forgets to take them at all. He always feels fine, though, so he does not think there is any kind of problem. At his annual check-up, Mr. S.'s doctor explains that his high blood pressure and high cholesterol are getting worse - putting him at risk for a heart attack, a stroke, or even death. They discuss how Mr. S. is taking his medicine, and when asked Mr. S. assures the doctor he knows how he is supposed to take his medicine. Mr. S. feels like taking his medication should be simple, and he shouldn't have any questions.

# Stigma
## Vignettes

Corrigan, P., Markowitz, F. E., Watson, A., Rowan, D., & Kubiak, M. A. (2003). An attribution model of public discrimination towards persons with mental illness. Journal of Health and Social Behavior, 162-179.

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| | | |
|---|---|---|
| **Pity** | I would feel pity for Mr. S.<br>How much sympathy would you feel for Mr. S?<br>How much concern would you feel for Mr. S? | |
| **Anger** | I would feel aggravated by Mr. S.<br>How angry would you feel at Mr. S?<br>How irritated would you feel at Mr. S? | **9-Pt Likert Scales** |
| **Personal Responsibility** | How controllable, do you think, is Mr. S's ability to use medicine correctly?<br>How responsible, do you think, is Mr. S for being able to use medicine correctly? | |

# Study Sample

N = 4, 974

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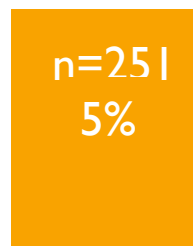| Table 1 | |
|---|---|
| Average Age (SD) | 43.5 (16.7) |
| | % (n) |
| Work in healthcare | 12.1 (603) |
| Gender | |
| Male | 42.3 (2,102) |
| Race | |
| White | 63.2 (3,146) |
| Hispanic | 13.5 (671) |
| African American | 16.0 (794) |
| Asian | 4.4 (218) |
| Other | 2.4 (121) |
| Education | |
| 2-Year College Degree or Higher | 59.9 (2,980) |
| Household Income | |
| Below $10,000 | 4.6 (230) |
| $10,000-49,999 | 38.3 (1,908) |
| $50,000-99,000 | 35.5 (1,764) |
| $100,000 and over | 21.5 (1,068) |

# RQ1:

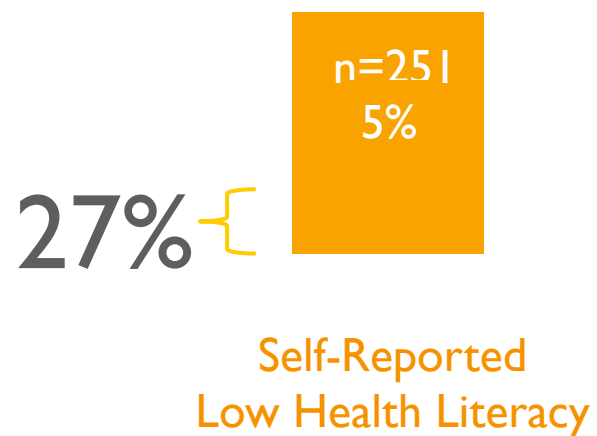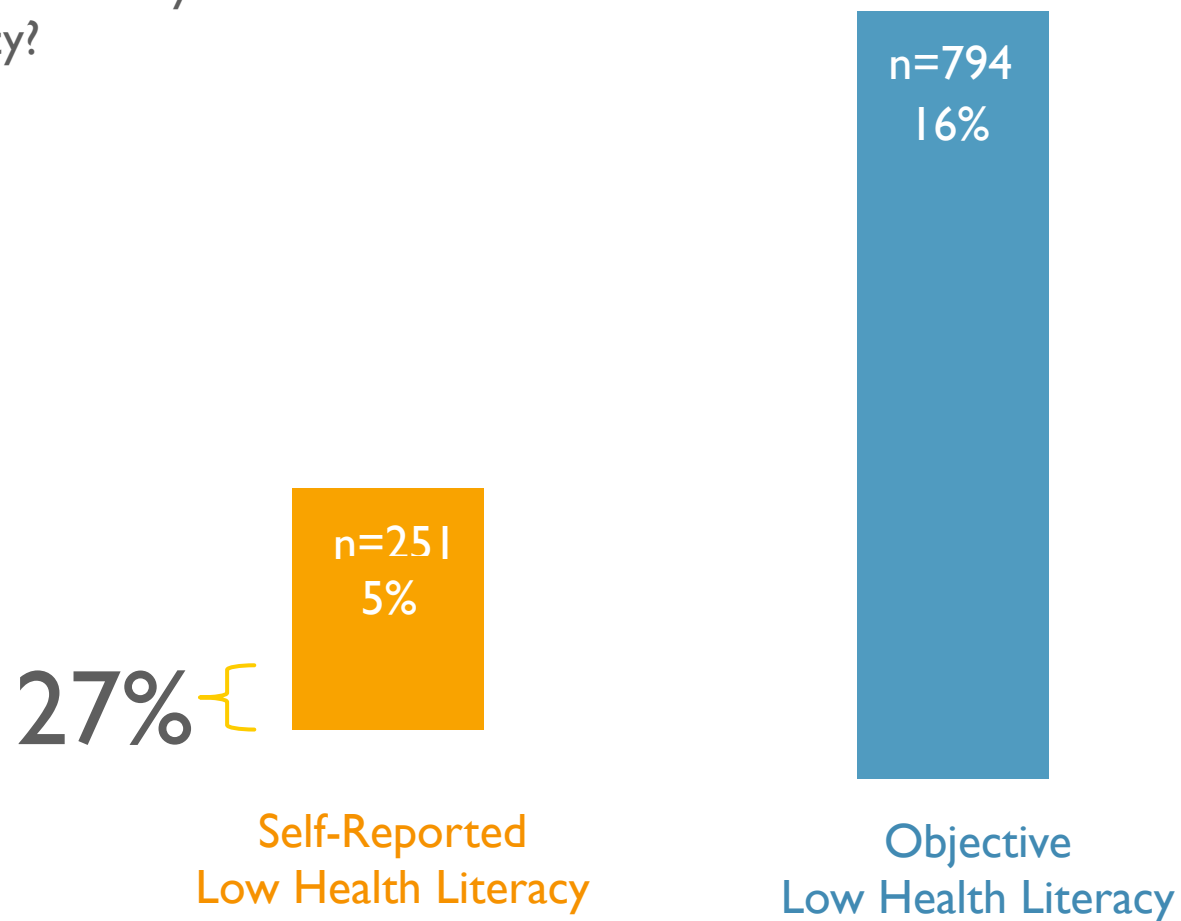How does participants' *self-reported* health literacy compare to their *measured* health literacy?

# RQ1:

How does participants' *self-reported* health literacy compare to their *measured* health literacy?

n=251
5%

**Self-Reported
Low Health Literacy**

# RQ1:

How does participants' *self-reported* health literacy compare to their *measured* health literacy?

n=251
5%

27%

Self-Reported
Low Health Literacy

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16%

n=251
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27%

Self-Reported
Low Health Literacy

Objective
Low Health Literacy

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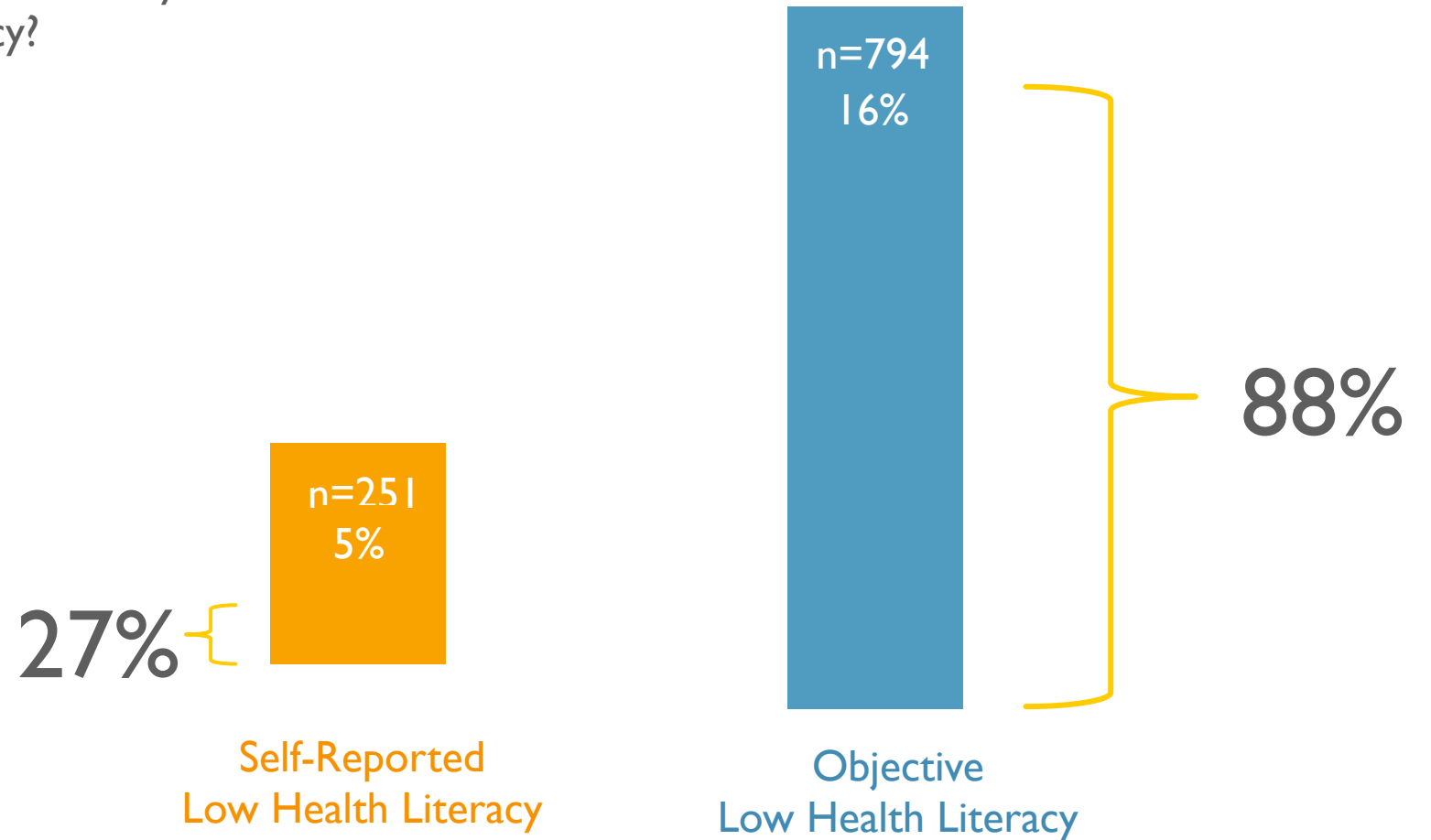How does participants' *self-reported* health literacy compare to their *measured* health literacy?

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88%

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Self-Reported
Low Health Literacy

Objective
Low Health Literacy

# RQ2:

How does one's level of health literacy influence their perceptions of stigma related to others' health literacy?

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How does one's level of health literacy influence their perceptions of stigma related to others' health literacy?

| Means, standard deviation, t-tests for stigma scales | | | | | | |
|---|---|---|---|---|---|---|
| **Scale** | Subjective Health Literacy | | | Objective Health Literacy | | |
| | Higher M (SD) | Lower M (SD) | T-Test | Higher M (SD) | Lower M (SD) | T-Test |
| **All vignettes** | | | | | | |
| **Pity** | 5.99 (1.82) | 5.67 (1.85) | t (4942) = -3.143** | 6.01 (1.77) | 5.75 (2.06) | t (4948) = -3.688*** |
| **Anger** | 5.04 (2.32) | 5.22 (2.25) | t (4935) = 1.413 | 5.02 (2.31) | 5.25 (2.37) | t (4941) = 2.527* |
| **Personal responsibility** | 5.39 (1.99) | 5.32 (1.95) | t (4932) = -0.637 | 5.49 (1.95) | 4.86 (2.06) | t (4937) = -8.173*** |
| **Vignette 1** | | | | | | |
| **Pity** | 5.77 (1.88) | 5.50 (1.81) | t (2486) = -1.923 | 5.82 (1.82) | 5.40 (2.11) | t (2488) = -4.094*** |
| **Anger** | 5.55 (2.29) | 5.69 (2.13) | t (2482) = 0.774 | 5.53 (2.26) | 5.75 (2.34) | t (2428) = 1.748 |
| **Personal responsibility** | 5.67 (1.97) | 5.57 (1.97) | t (2478) = -0.680 | 5.78 (1.93) | 5.07 (2.09) | t (2480) = -6.545*** |
| **Vignette 2** | | | | | | |
| **Pity** | 6.21 (1.73) | 5.88 (1.89) | t (2454) = -2.430* | 6.20 (1.70) | 6.09 (1.95) | t (2458) = -1.098 |
| **Anger** | 4.53 (2.24) | 4.71 (2.28) | t (2451) = 0.984 | 4.50 (2.23) | 4.75 (2.30) | t (2455) = 2.013* |
| **Personal responsibility** | 5.11 (1.96) | 5.05 (1.91) | t (2452) = -0.393 | 5.20 (1.93) | 4.65 (2.04) | t (2455) = -5.059*** |
| * = significant at p < .05, ** = significant at p < .01, *** = significant at p < .001 | | | | | | |

# RQ2:

How does one's level of health literacy influence their perceptions of stigma related to others' health literacy?

| Means, standard deviation, t-tests for stigma scales | | | | | | |
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| | Higher M (SD) | Lower M (SD) | T-Test | Higher M (SD) | Lower M (SD) | T-Test |
| **All vignettes** | | | | | | |
| **Pity** | 5.99 (1.82) | 5.67 (1.85) | t (4942) = -3.143** | 6.01 (1.77) | 5.75 (2.06) | t (4948) = -3.688*** |
| **Anger** | 5.04 (2.32) | 5.22 (2.25) | t (4935) = 1.413 | 5.02 (2.31) | 5.25 (2.37) | t (4941) = 2.527* |
| **Personal responsibility** | 5.39 (1.99) | 5.32 (1.95) | t (4932) = -0.637 | 5.49 (1.95) | 4.86 (2.06) | t (4937) = -8.173*** |
| **Vignette 1** | | | | | | |
| **Pity** | 5.77 (1.88) | 5.50 (1.81) | t (2486) = -1.923 | 5.82 (1.82) | 5.40 (2.11) | t (2488) = -4.094*** |
| **Anger** | 5.55 (2.29) | 5.69 (2.13) | t (2482) = 0.774 | 5.53 (2.26) | 5.75 (2.34) | t (2428) = 1.748 |
| **Personal responsibility** | 5.67 (1.97) | 5.57 (1.97) | t (2478) = -0.680 | 5.78 (1.93) | 5.07 (2.09) | t (2480) = -6.545*** |
| **Vignette 2** | | | | | | |
| **Pity** | 6.21 (1.73) | 5.88 (1.89) | t (2454) = -2.430* | 6.20 (1.70) | 6.09 (1.95) | t (2458) = -1.098 |
| **Anger** | 4.53 (2.24) | 4.71 (2.28) | t (2451) = 0.984 | 4.50 (2.23) | 4.75 (2.30) | t (2455) = 2.013* |
| **Personal responsibility** | 5.11 (1.96) | 5.05 (1.91) | t (2452) = -0.393 | 5.20 (1.93) | 4.65 (2.04) | t (2455) = -5.059*** |
| * = significant at p < .05, ** = significant at p < .01, *** = significant at p < .001 | | | | | | |

# RQ3:

How do demographic characteristics of a person with lower health literacy influence stigmatized perceptions?

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How do demographic characteristics of a person with lower health literacy influence stigmatized perceptions?

## Person included in vignette:

- Sex: Male // Female patient
- Age: 33 y.o. // 72 y.o. patient
- Race/Ethnicity: White // Hispanic // African American patient
- Insurance: Medicare // Medicaid

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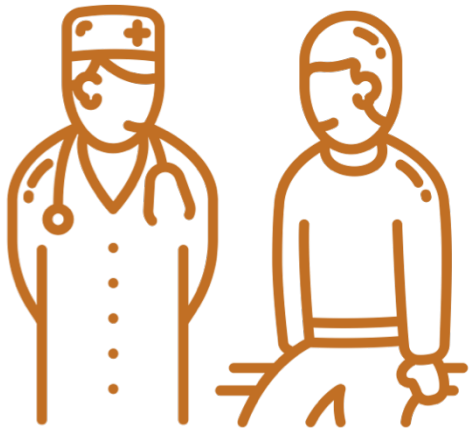| Pity | Anger | Personal Responsibility |
|------|-------|------------------------|
| $M_{33}=5.75$ | $M_{33}=5.57$ | $M_{33}=5.67$ |
| $M_{72}=6.18$ | $M_{72}=4.54$ | $M_{72}=5.12$ |

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**33 y.o.** self-reported

| Pity | Anger | Personal Responsibility |
|------|-------|------------------------|
| $M_{Low}$=5.50 | | |
| $M_{High}$=5.77 | | |

**33 y.o.** objective

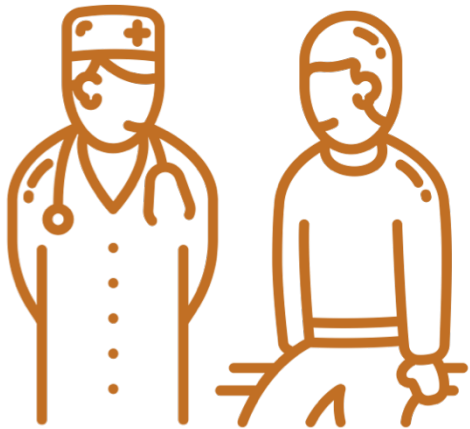| Pity | Anger | Personal Responsibility |
|------|-------|------------------------|
| | $M_{Low}$=5.40 | $M_{Low}$=5.07 |
| | $M_{High}$=5.82 | $M_{High}$=5.78 |

# RQ3:

How do demographic characteristics of a person with lower health literacy influence stigmatized perceptions?

| Pity | Anger | Personal Responsibility |
|------|-------|-------------------------|
| $M_{33}=5.75$ | $M_{33}=5.57$ | $M_{33}=5.67$ |
| $M_{72}=6.18$ | $M_{72}=4.54$ | $M_{72}=5.12$ |

# RQ3:

How do demographic characteristics of a person with lower health literacy influence stigmatized perceptions?

| Pity | Anger | Personal Responsibility |
|---|---|---|
| $M_{33}=5.75$ | $M_{33}=5.57$ | $M_{33}=5.67$ |
| $M_{72}=6.18$ | $M_{72}=4.54$ | $M_{72}=5.12$ |

**72 y.o.** self-reported

| Pity | Anger | Personal Responsibility |
|---|---|---|
| $M_{Low}=5.87$ | | |
| $M_{High}=6.21$ | | |

**72 y.o.** objective

| Pity | Anger | Personal Responsibility |
|---|---|---|
| | $M_{Low}=4.75$ | $M_{Low}=4.65$ |
| | $M_{High}=4.50$ | $M_{High}=5.20$ |

# So What?

# So What?

How does the general public view low health literacy?

# So What?

## How does the general public view low health literacy?

Differed by own health literacy abilities.

# So What?

How does the general public view low health literacy?

Differed by own health literacy abilities.

Low HL

Adequate HL

# So What?

How does the general public view low health literacy?

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Low HL ↑ Anger
↓ Pity

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# So What?

How does the general public view low health literacy?

Differed by own health literacy abilities.

Low HL ↓ Personal Responsibility

Adequate HL

# So What?

Stigma may exacerbate negative outcomes associated with low health literacy.

# So What?

Stigma may exacerbate negative outcomes associated with low health literacy.

Incorporate into programs and interventions.

# THANKS!

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Center for Identity