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## Social Needs Data Collection and Use: Perspectives from Patients and Providers

Chelsea Richwine, Economist, Data Analysis Branch, Office of Technology, ONC



#### **Data**

- Hospital Survey: 2022 American Hospital Association (AHA) Annual Survey and Information Technology (IT) Supplement
  - The annual survey asks hospitals if they have programs or strategies to address 9 specific health-related social needs and whether they screen patients for these needs. Fielded March to August 2022. Analyses restricted to IT Supplement respondents with complete data for social needs questions (N = 1,997).
  - The IT Supplement asks about hospitals' collection, receipt, and use of data on patients' health-related social needs. Fielded July to December 2022, yielding a sample of 2,541 non-federal acute care hospitals (58% response rate)
- Physician Survey: 2022 National Physician Health IT Survey
  - Asks about physicians' methods of documenting social needs screening and perceived importance of accessing social needs data in the EHR
  - Fielded April to November 2022, yielding a sample of **3,006 physicians** who provided outpatient care and used an EHR (3.6% response rate)
- Patient Survey: 2022 Health Information National Trends Survey (HINTS 6)
  - Asks about individuals' comfort with their provider sharing their social needs information with other providers for their treatment purposes.
  - Fielded March to November 2022, yielding a sample of **6,252 U.S. adults** (28% response rate).

### **AHA IT Supplement Results**

### In 2022, most hospitals collected social needs data, and more than half electronically received data from outside sources

Hospitals' collection and receipt of social needs data from outside sources

No collection, 17%

Collect, but <u>not</u> routinely 29%

Collect routinely, 54%

No receipt, 40%

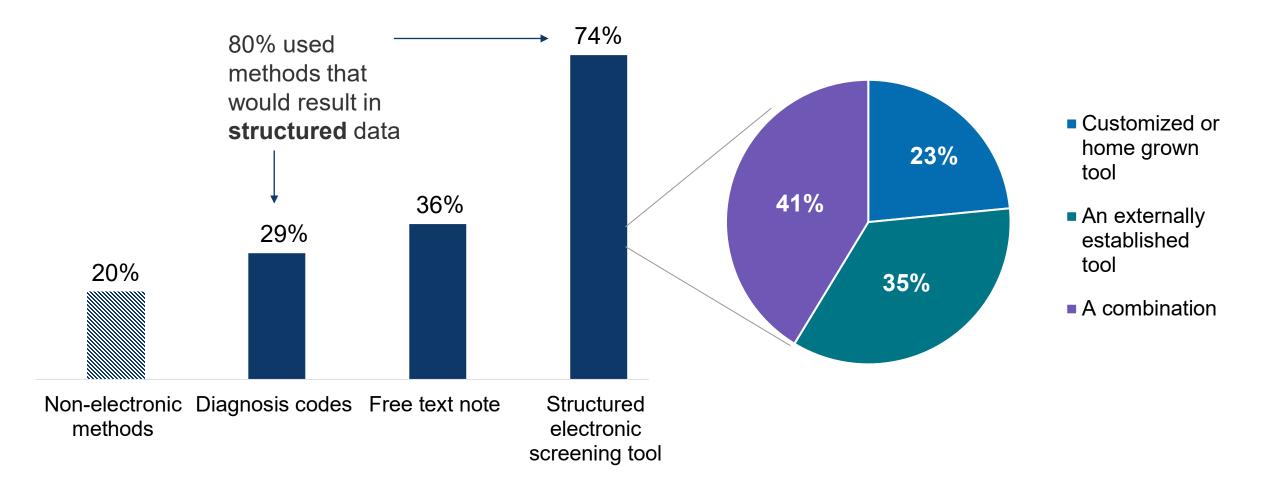
Receive from outside sources, 60%

Collect Social Needs Data

Receive Social Needs Data

### Nearly three-quarters of hospitals used a structured electronic screening tool to collect social needs data

Methods and tools used for social needs screening among hospitals that reported collecting social needs data at their hospital



#### Rates of routine screening were higher among large, systemaffiliated, urban hospitals compared to their counterparts

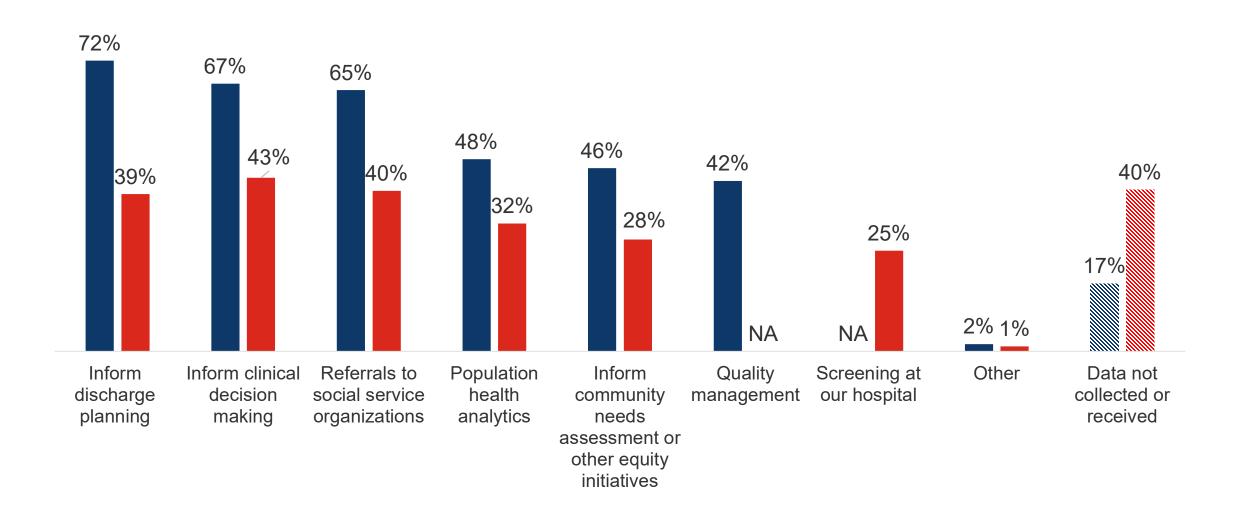
| Hospital Characteristics       | Collect social needs data routinely (54%) | Use structured screening tool or diagnosis codes (80%) |
|--------------------------------|---|--|
| Hospital Size                  |   |  |
| Smal                           | l 49%                                     | 80%  |
| Medium-Large                   | e 60%*                                    | 80%  |
| Critical Access Hospital (CAH) |   |  |
| CAH                            | 46%                                       | 82%  |
| non-CAH                        | 57%*                                      | 79%  |
| Location                       |   |  |
| Rura                           | I 46%                                     | 82%  |
| Suburban-Urbar                 | 61%*                                      | 84%  |
| System Affiliation             |   |  |
| Independent                    | t 44%                                     | 79%  |
| System Affiliated              | 59%*                                      | 80%  |
| Ownership                      |   |  |
| For-profit (ref                | 24%                                       | 27%  |
| Non-profi                      | t 65%*                                    | 92%*   |
| Government Owned               | 41%*                                      | 77%*   |
| Social deprivation index (SDI) |   |  |
| Top 20                         | 53%                                       | 80%  |
| Bottom 80                      | 54%                                       | 80%  |

### The top 3 uses of social needs data were to inform clinical decision making or discharge planning and to make referrals

#### Uses of social needs data collected internally or received from outside sources

■ Collected at hospital

■ Received from outside sources



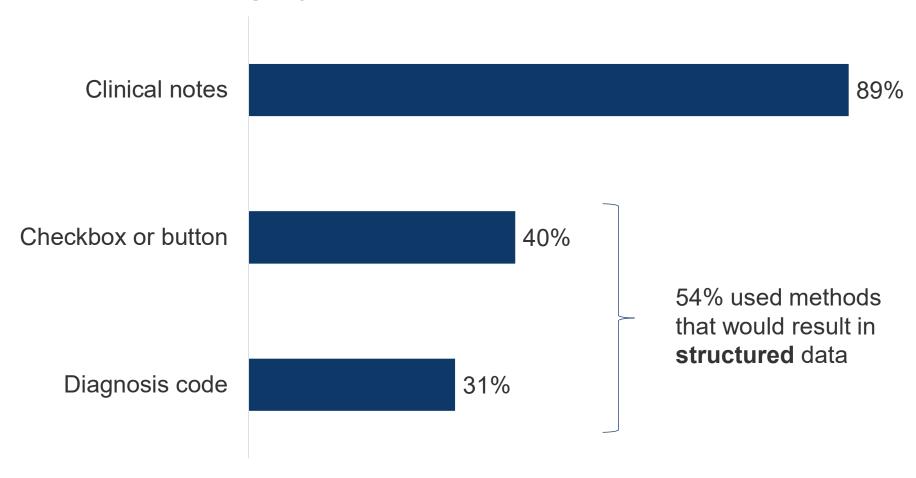
### Social needs data collection and use was higher among hospitals with programs or strategies to address these needs

|                                 | Data collection                   |               | Data use              |                     |                            |
|---------------------------------|-----------------------------------|---------------|-----------------------|---------------------|----------------------------|
| Program or Strategy to address: | Screen for respective social need | Any screening | Discharge<br>planning | Making<br>referrals | Community needs assessment |
| Housing: Yes                    | 94%                               | 86%           | 76%                   | 72%                 | 53%                        |
| No                              | 57%                               | 71%           | 63%                   | 58%                 | 36%                        |
| Food insecurity: Yes            | 92%                               | 87%           | 76%                   | 74%                 | 53%                        |
| No                              | 46%                               | 65%           | 58%                   | 51%                 | 31%                        |
| Transportation: Yes             | 91%                               | 84%           | 74%                   | 71%                 | 50%                        |
| No                              | 44%                               | 69%           | 61%                   | 53%                 | 35%                        |

#### **UCSF Physician Survey Results**

### In 2022, 63% physicians used one of three methods to document screening for social needs in their EHR

Methods used to document screening for social needs in the EHR among physicians who used at least 1 of 3 methods



### Screening rates are highest among primary care physicians, those practicing in FQHCs, and with >50% of vulnerable patients

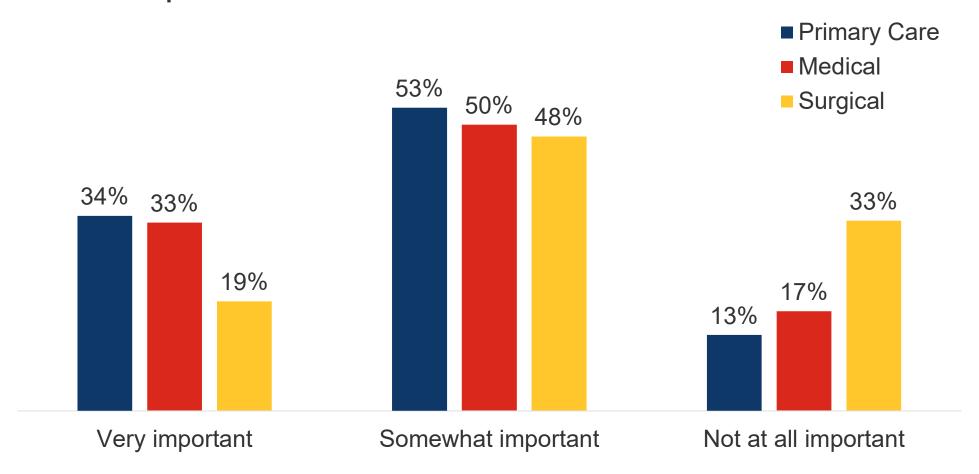
| Physician and Practice Characteristics  | Document Social Needs  |  |
|---|------------------------|--|
|   | Screening in EHR (63%) |  |
| Physician Specialty   |                        |  |
| Primary care (ref)  | 76%                    |  |
| Medical   | 60%*                   |  |
| Surgical  | 34%*                   |  |
| Practice Setting  |                        |  |
| Private solo or group practice, freestanding clinic, urgent care center (ref) | 55%                    |  |
| Integrated Delivery System, HMO, health system or other prepaid practice      | 55%                    |  |
| Academic health center / faculty practice                                     | 66%*                   |  |
| Hospital outpatient department  | 62%                    |  |
| FQHC or Look-Alike or Rural Heath Clinic                                      | 84%*                   |  |
| Other   | 74%*                   |  |
| Value-based Care Participation  |                        |  |
| Yes (ref)   | 70%                    |  |
| No  | 52%*                   |  |
| Don't know  | 54%*                   |  |
| % Patients vulnerable patients  |                        |  |
| <10% (ref)  | 47%                    |  |
| 10-49%  | 65%*                   |  |
| >50%  | 77%*                   |  |
| Don't know  | 53%                    |  |

**HMO** = Health Maintenance Organization

**FQHC** = Federally Qualified Health Center

### Most physicians reported it is very or somewhat important to have access to social determinants of health (SDOH) information from other health systems/organizations

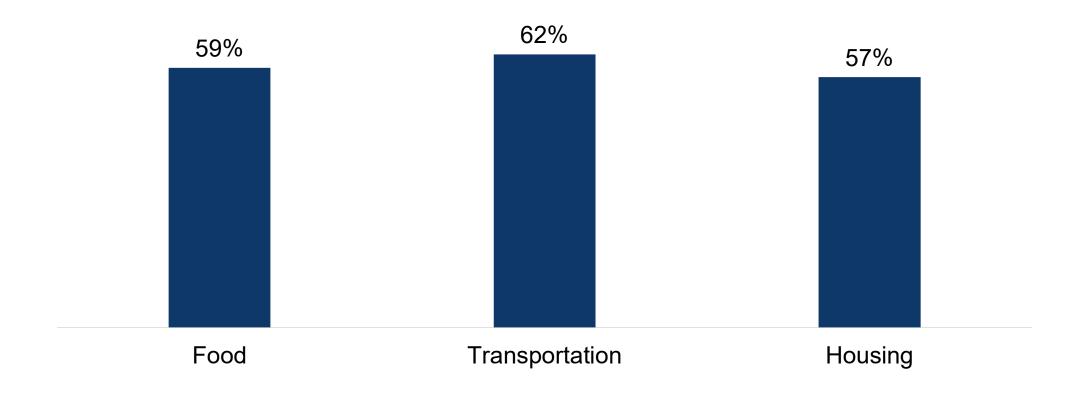
Importance of accessing SDOH information electronically in the EHR and/or portal





### About 6 in 10 individuals nationwide reported they would be comfortable with social needs information sharing for treatment-related purposes

Individuals' comfort with providers sharing information with each other for their treatment purposes related to the following social needs:

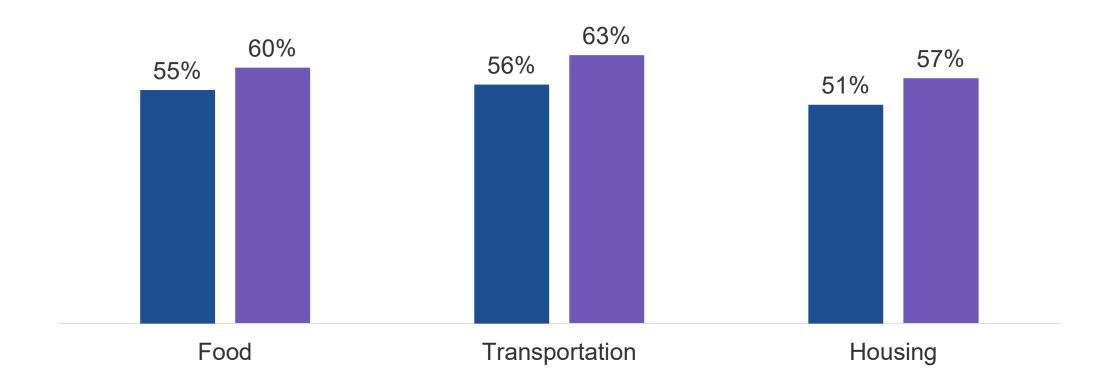


### Comfort with social needs information sharing was slightly lower among individuals who recently experienced that social need

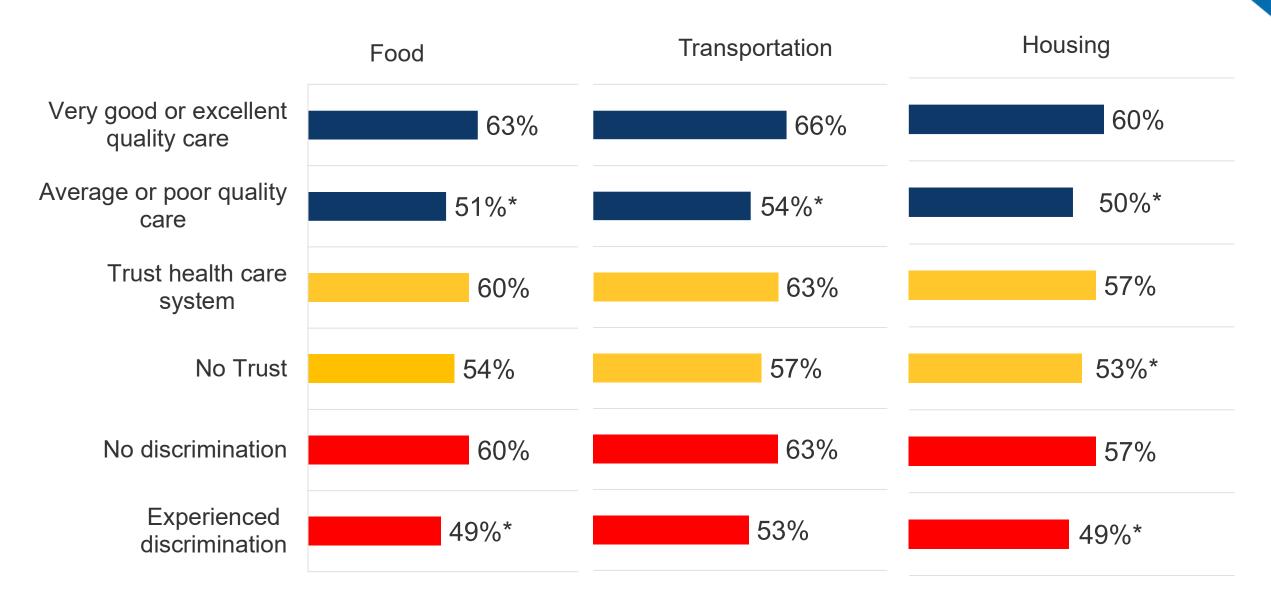
Individuals' comfort with their providers sharing social needs information with each other for treatment purposes, by experience with social need

■ Recently experienced social need

■ No recent history of social need



### Comfort with social needs information sharing varied by personal experiences in health care



#### **Discussion**

- Together, these data sources provide 3 different perspectives on the collection and use of social needs data in inpatient and outpatient settings
  - Findings from the hospital and physician surveys indicate:
    - <u>Hospitals frequently screen for social needs</u>, but rates are lower among lower-resourced hospitals and higher among those with programs and strategies in place to address social needs.
    - Many physicians document social needs screening in their EHR, but rates are higher among primary care physicians and those incentivized to screen (e.g., participate in value-based care)
    - Structured data collection—which facilitates exchange and subsequent use of data—is more prevalent in hospital settings (physicians more commonly use free-text notes)
  - Findings from the patient survey suggest <u>a majority of patients are comfortable with social needs</u> <u>information sharing for treatment purposes</u>, but comfort varies based on personal experiences.
- Ongoing measurement will be important for:
  - Tracking progress in social needs screening and documentation practices using methods that will support the exchange and use of data for informing treatment and making referrals to social services.
  - Informing efforts to increase patients' comfort with social needs information sharing and confidence that data collected are being used to help patients get the resources they need.

### Social Determinants of Health Information in the EHR: Patient and Clinician Views

Office of the National Coordinator for Health Information Technology Annual Meeting Catherine DesRoches Director, OpenNotes Associate Professor Division of General Medicine

#### Overview of Project

#### **Justification**

- SDOH are either not captured in the EHR at all or not in a standardized and useful way.
- How can they be captured in the EHR to better enable their use for improving care?
- What hopes and concerns to both patients and providers have?

#### **Purpose**

 Provide recommendations to ONC on how SDOH can be more effectively captured and utilized to improve care.

#### Focus Groups

- Ten live patient groups conducted virtually
  - Black/African American (2 groups), Spanish speakers, rural, underserved areas, e-patients, persons with disabilities, care partners of children, age 65+, LGBTQ+
- Ten asynchronous health care professional groups conducted virtually
  - Primary care providers, safety net providers, pediatrics, emergency medicine, case management, mental health, specialty care (includes OT/PT/Nutrition)

#### HC Professionals: Current Practices

- General agreement: it's important to ask about SDOH
- Most do ask about SDOH
- Most don't explain to patients why they are asking or that they are documenting
  - Will explain if asked
  - Most likely to explain-pediatricians, case managers, mental health providers

#### HC Professionals: Current Practices

- Collected in a variety of ways:
  - >Patient-completed paper form during the visit
  - >Medical Assistant, Social Worker, Registered Nurse, Clinician ask patients (often others first and then clinician discusses)
- Not often collected via portal questionnaire, iPad, or kiosk in the waiting room.
- Most don't get SDOH from outside sources
  - >more common in pediatrics, emergency medicine, mental health
  - Most common sources: social work, emergency department visits, school, foster care, social service agencies, first responders.
  - >most do not share with outside providers/agencies-occasional in pediatrics

#### Patients: Experiences with Being Asked about SDOH

- 1. Most commonly asked about income and employment
- 2. Hard to distinguish between being asked about SDOH and other pre-visit work
- 3. Can be irritating, but agree both forms and conversation are important
  - Form: allows privacy, time to think, reduce chance of errors, info to clinician in advance to prepare;
  - Conversation: delve more deeply into particular areas as needed
  - "I fill out all of the forms on the portal then they ask me the same questions when I get there..." (age 65+ patients)
- 4. Can both promote and erode trust

#### Patients: Ask/Don't Ask?

General agreement that clinicians should know about factors that affect their health.

But disagreement about what those factors are.

| What do patients want to be about?                       | What do patients NOT want to be asked about? |
|--|--|
| <ul><li>Transportation problems</li><li>Safety</li></ul> | • INCOME                                     |
| <ul> <li>Sexual orientation</li> </ul>                   | Sexual orientation                           |
|  |  |

Only ask if can assist!

#### Patients: Trust of Clinician is Key

#### A good and ongoing relationship can facilitate the conversation

- > a poor/intermittent relationship is a barrier
- "And I think it's because of the doctor that I do have now that I am more open because we built that relationship." - Black Patient Group
- "Any more than I want my neighbors to know what's going on, I don't want my doctor to know either." - Rural Patient Group
- "Tell me why you need to know..." Patients with Disabilities Group

Distrust came up more often in these groups: black patients, parents, rural patients.

Also found overall health system distrust across groups regarding racism, classism, ableism.

#### Patient: Fear that Information Will be Used Against Them

- "I think we probably just need to change the culture around how I feel like it's being perceived by the doctor. If I felt like I had a doctor who would read that and never not listen to me because of it or something like that, then I'm down for him to know...but I think it's when I feel like it's being used almost against me or to not give me the help that I need, that's when it's a problem." (Black/African-American patient group)
- "I wouldn't want anyone to base my healthcare off how much money I make, or anything like that.. I wouldn't want anyone to try to judge or try to belittle me or not give me the care that I need." (underserved areas patient group)

#### Parents: Fear and Trust

- "And they see it as, oh well she's not able to provide financially for her kids. So next thing you know, **CPS** is showing up at my door."
- "It makes me happy that they are asking because many people wouldn't just be forward with their provider...! do sometimes wonder, they're asking these questions but also do they have the, hopefully they also have the training to handle not, that not biasing their opinions about the patient because that is, that information can change sometimes how you think about people. So it makes you just kind of like I'm OK with sharing it but also it makes me wonder like how will they receive it?" (care partners for children group)

#### Patients: Ambivalence about Sharing Information

- "You know that actually the doctors are not the only one looking in your files. You've got all the nurses that's in there. You put your trust in them. You don't know who knows who. You don't know who knows you and they're getting your information. So that's another concern." Black Patient Group
- "If it's not relevant to the care I need, I don't think it should be shared." Rural Patient Group

### HC Professionals: Current Practices How is SDOH Information Used?

- Utilize SDOH for:
  - patient care/informing treatment decisions
  - referrals and resources within practice (eg. SW) and outside
  - In the ER: utilize for discharge decisions and discharge instructions
- Small number of health systems/clinics utilize for research/population tracking/community needs assessment
  - Most are not aware of whether their organization is using the information in this way.

### HC Professionals: Preferred Practices What Would They Want Collected?

- Types SDOH would be most useful to collect:
- Some said all because needs are unique to each patient
- Others with many responses:
  - financial/socioeconomic status
  - housing
  - food
  - transportation
  - languages
  - social supports
- "Preferred language, and transportation access would be the best determinants and useful, because they can aid in giving the patient good access for follow up care where needed, or specialty treatment that would coincide with their "limitations "i.e. wouldn't send someone to a specialist 20 miles away if they didn't have transportation..." (PCP group-Adult, Urban, Underserved)

Note: This mirrors a concern raised in the patient groups about how the information could be used to limit their care.

### Patients Want Control Over What is Shared with Others

- Misunderstanding about the HIPAA forms they are signing
- Would like to designate what can be shared and with whom (specific to individual data elements)
- Want only relevant info shared (with permission or their control)
- Don't want information shared with clinicians who rarely see them
- Concern could bias future providers who see this information

"I think I'd like to know if this information is being shared and to whom. There ought to be a "hide" button on each social determinant answer to keep some answers confidential to other providers." (e-patient group)

#### Primary Themes

- Data collection is not consistent.
- Trust is key can be a facilitator or barrier
- Patients are ambivalent about their information being shared.
  - Patients want the ability to segment their SDOH data.
  - Patients want to be asked to give permission for SDOH information to be shared.
  - Patients do not want to be asked if the practice cannot provide resources.
    - And providers do not like to ask in these situations...

### Questions?

cdesroch@bidmc.harvard.edu

# ONC Annual Meeting Patient and Clinical Perspectives and Approaches on the Documentation, Exchange, and Use of Social Needs and SDoH Data: Implications for Clinical Care and Downstream Use 14 November 2023

SHIFT'

#### Hannah Galvin, MD, FAAP, FAMIA, CHCIO, CDH-E

Chief Medical Information Officer, Cambridge Health Alliance Assistant Professor of Medicine, Tufts University School of Medicine Instructor in Pediatrics, Harvard Medical School Board Chair, Co-Founder, Shift





The independent health care task force for equitable interoperability

## **Patient Voices**

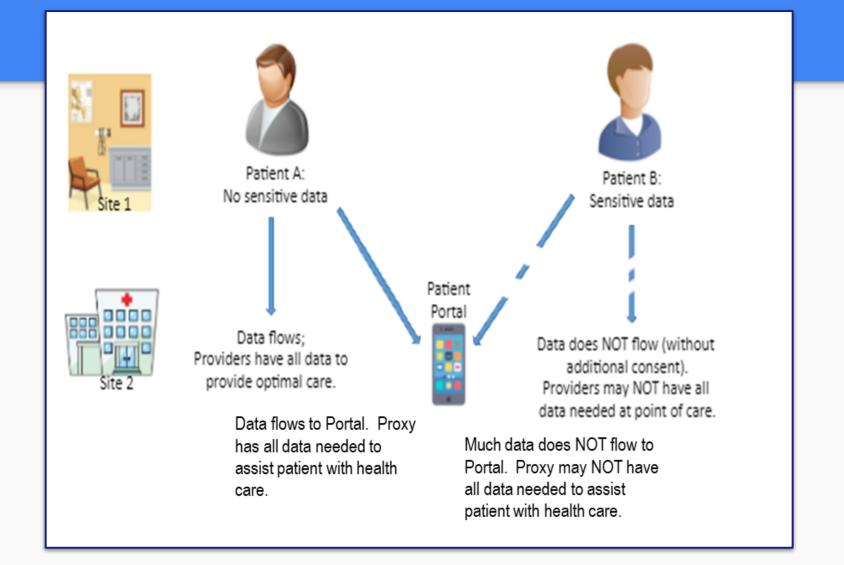








## Equitable Interoperability: Defining the Problem





## Shift

- Founded 2018, formalized 2020
- Mission: To advance safe, equitable, and patient-empowered sharing of health information.
- Vision: To further a health care ecosystem in which better standards for clinical data sharing
  increase trust between patients, providers, and caregivers to improve quality of care and health
  equity.



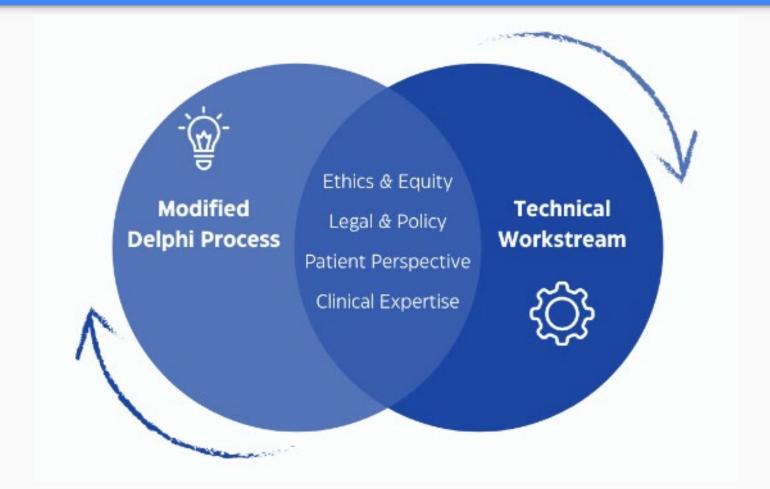
## **Governing Board**

- American Medical Association
- American Academy of Pediatrics
- Integrating the Healthcare Enterprise USA
- Electronic Healthcare Records Association
- Drummond Group
- Office of the National Coordinator for Health IT (ex-officio)

Searching for a national patient advocacy organization to replace AARP



## Shift's Approach





## Shift Deliverables

- -Reference implementations → real life implementation
- -Updated DS4P FHIR standard/PCF profile according to Shift use cases and implementation guidance
- -Compendium IG based on consensus-driven implementation guidance from modified Delphi process
- -Recommendations for semantic conceptual framework of commonlyconsidered sensitive data elements; selection of VSAC steward



## **Future Vision**

Once Shift has demonstrated matured application of patient-driven data sharing leveraging expanded DS4P FHIR standard and consensus-based implementation guidance endorsed by industry stakeholders, we look forward to working with ONC to drive widespread adoption through policy.



## Interested in Learning More?

## http://www.shiftinterop.org

contact@shiftinterop.org

Interest Form: <a href="https://bit.ly/SHIFTINTEROP">https://bit.ly/SHIFTINTEROP</a>



# Addressing Social Needs at the CMS Innovation Center

Sarah Downer, JD

December 14, 2023 – ONC Annual Meeting

Sarah.downer@cms.hhs.gov



## **Accountable Heath Communities Model Design**

#### **Assistance Track**

Universal screening to identify people with Medicare and/or Medicaid with HRSNs
Referral and navigation assistance to connect eligible patients with needed community services; randomized evaluation design

#### **Alignment Track**

Universal screening, referral, and navigation Community-level quality improvement activities engaging key stakeholders to align community service capacity with unmet needs

#### Five Core Health-Related Social Needs



**Housing Instability** 



**Food Insecurity** 



**Transportation Needs** 



**Utility Needs** 



**Interpersonal Violence (Safety)** 



## **Lessons from AHC**

## Screening, referral, and navigation are **feasible**, **appropriate**, and **scalable**

Over 1.8 million screenings of people with Medicare, Medicaid, or both across widely varied clinical settings from big EDs to community health fairs

Over 75% accepted navigation when offered; acceptance did not differ by program enrollment, type of need, sociodemographic characteristics



## **Lessons from AHC**

## HRSNs are **extremely common** among people with Medicare and/or Medicaid

Almost 40% screened positive for one or more of the core HRSN

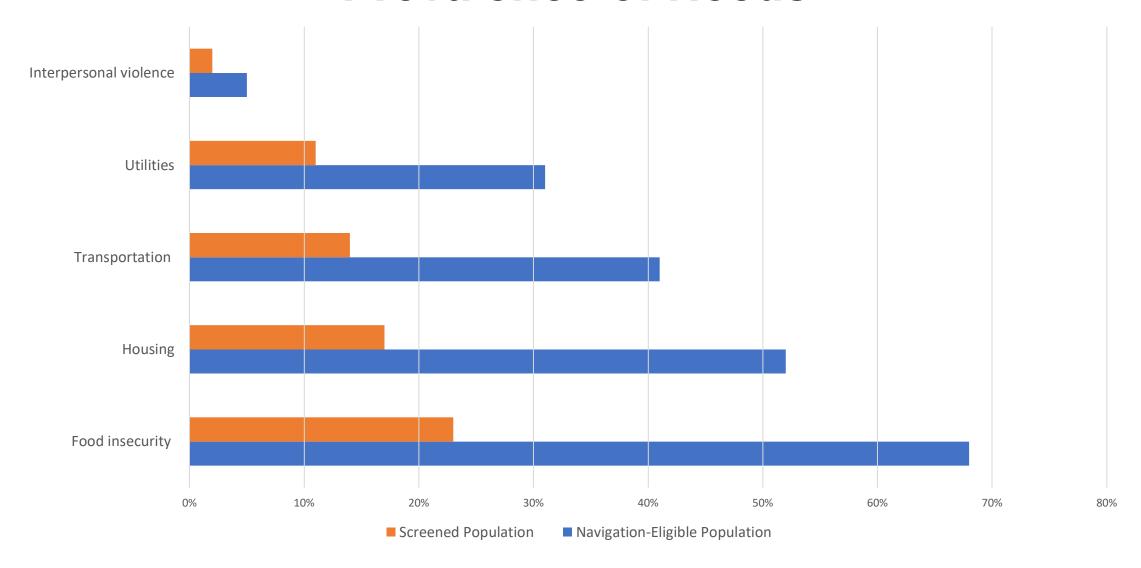
Nearly 1 in 5 (19%) had more than one HRSN

Out of all individuals with an HRSN:

- 63% had a food need
- 47% had a housing need
- 37% had a transportation need
- 30% had a utility need



## **Prevalence of Needs**





## **Lessons from AHC**

## Navigation reduced Emergency Department (ED) use—but didn't always resolve needs

### **Utilization Impacts**

(Assistance Track)

- 3% reduction in ED visits for people with Medicaid
- 8% reduction in ED visits & 9% reduction in avoidable ED visits for people with Fee-for-service (FFS) Medicare
- Bigger impacts for people with Medicaid with multiple HRSN and non-White and/or Hispanic people with FFS Medicare

#### **Navigation challenges**

- Many people wanting services lost to follow-up (29%)
- Similar rates of connection with community services and needs resolution in the intervention and control groups



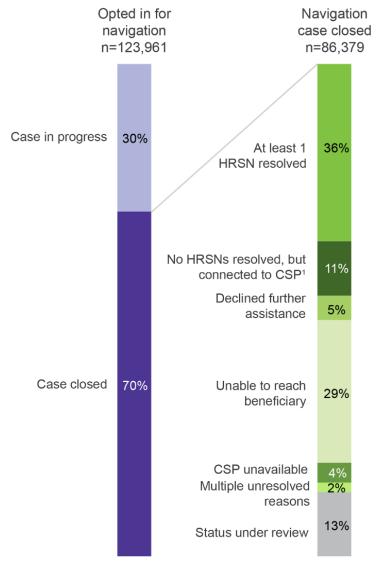
#### **Needs Resolved**

 Less than half of beneficiaries were connected to a Community Service Provider (CSP) or had any of their HRSNs resolved

- Of those with a closed navigation case:
  - 36% had at least one need resolved
  - 11% connected to a CSP, but no need resolved

### **Challenges: Resource Availability**

- Beneficiaries, navigators, and CSPs described challenges connecting beneficiaries with community resources
- Community resource availability varied across bridge organization geographical target areas
- Community resource availability not always matched to population needs



<sup>&</sup>lt;sup>1</sup> Connected to CSP for at least 1 HRSN. Source: AHC screening and navigation data, May 2018—December 2021 Definitions: AHC = Accountable Health Communities; CSP = community service provider; HRSN = health-related social need.



## Taking Key Learnings Forward: The Challenge for CMMI

#### Screening

 Incorporate screening into existing workflows and pursue ways to integrate health-related social needs (HRSNs) data into clinical data to maximize use

#### Community Service Referral and Navigation

- Invest time in updating and tracking constantly evolving community resources
- Support navigator training, develop scripts, and facilitate warm handoffs between screener and navigator to increase patient engagement and acceptance of navigation

#### Community Alignment

- Addressing and resolving HRSNs is a major challenge in the field; invest in building capacity of community resources and, when possible, in closed loop referral systems
- Build strategic cross-sector partnerships by engaging advisory board, high-level leaders, sharing data, and joining existing local or regional collaboratives

#### Scale and Spread

- Culture change is required to implement, scale, and spread AHC Model activities; organizational leadership buy-in is key
- State Medicaid Agencies can consider innovations that support screening, referral, and navigation



## **CMS SDOH Landscape**

#### **Changes for People with Medicare Coverage**

- New codes in the Physician Fee Schedule; encouragement of Z codes
- <u>Inpatient Quality Reporting Program:</u> Drivers of Health Measures
- Center for Medicare's Advanced Investment Payments in the Medicare Shared Savings Program to directly address social needs
- Medicare Advantage (MA) Special Supplemental Benefits for the Chronically III
- Health equity index and health equity adjustment in Medicare Shared Savings Program and MA, to reward excellent care delivered to underserved populations

### **Changes for people with Medicaid Coverage**

- Many states are requiring Medicaid Managed Care Organizations to offer screening
- Addressing SDOH through 1115 waivers and in lieu of services



#### **CMMI Models**

- Social determinants of health strategy: Implementing HRSN screening across model portfolio
- Health-related social needs screening (HRSN)
  - ACO Realizing Equity, Access, and Community Health Model (ACO REACH)
  - Enhanced Oncology Model (EOM)
  - Integrated Care for Kids (InCK) Model
  - Maternal Opioid Misuse Model (MOM)
  - States Advancing AHEAD (AHEAD)
  - Making Care Primary (MCP)
  - Guiding an Improved Dementia Experience (GUIDE)
- Financial support for services that address HRSNs
  - Value-Based Insurance Design (VBID) Model



## Questions?

