advocacy CHATS

COA Patient Advocacy Network

Addressing Health Equity in the Healthcare System

Alan Balch, PhD
Chief Executive Officer
Patient Advocate Foundation
National Patient Advocate Foundation

Rose Gerber, M.S.
Director of Patient Advocacy & Education
Community Oncology Alliance

advocacy CHATS COA Patient Advocacy Network

Today's Chat Agenda

- **Updates: Community Oncology Alliance (COA) and COA's Patient Advocacy Network (CPAN)**
- **National Patient Advocacy Foundation Impact and Mission**
- **Health Equity: Science and Strategy**
- **Deliver Model for Person-Centered Care**

Learn more:
COA's Patient Advocacy Network: www.coaAdvocacy.org
Community Oncology Alliance: www.communityoncology.org
National Patient Advocate Foundation: www.npaf.org
Patient Advocate Foundation: www.patientadvocate.org

Patient Advocate Foundation

Patient Advocate Foundation Health Equity Initiatives (2014-2022)

PAF Impact 2021: Delivering Help & Hope

156,000 patients served

$22M obtained in debt relief by PAF Case Managers

$350MM provided in direct financial assistance

35 case management program & 50 financial assistance funds

18 non-profit and academic partnerships

30 students supported through PAF’s academic scholarship program

Patient Advocate Foundation

Our Mission

Patient Advocate Foundation (PAF) is a national 501(c)3 non-profit organization which provides case management services and financial aid to Americans with chronic, life-threatening and debilitating illnesses.

25TH ANNIVERSARY

PROGRAMS AND SERVICES

Direct Patient Services

- CASE MANAGEMENT
- FINANCIAL ASSISTANCE FUNDS
- CO-PAY RELIEF PROGRAM
- HEALTH EQUITY & COMMUNITY ENGAGEMENT
- PATIENT IMPACT
- SPECIAL EVENTS
- HEALTH SERVICES, RESEARCH, PATIENT EXPERIENCE & EVALUATION
- PATIENT EDUCATION & EMPOWERMENT

Outreach

PAF Health Equity Version 1.0

(FY 2014 – FY 2020)

2014: Health Equity Initiative Launch

- Objective: Expand the level at which current and existing PAF programs effectively reach and serve patients facing inequities in the health care system.

- Key drivers:
  - establish organizational goals and metrics
  - hire an executive leader

2014 Board Level Goal: diversify the PAF patient population

Objective: Expanding programs and services to specific patient populations with acute needs based on disease and race/ethnicity

- Key indicators:
  - Serve more patients with different diseases
  - Serve more patients from racial and ethnic groups with an emphasis on Hispanic Latinos and African Americans.
  - Number of relationships with organizations representing racial and ethnic minority groups
  - Number of relationships with different patient organizations
  - New programs specifically for racial and ethnic minorities

Shonta Chambers

PAF's EVP for Health Equity Initiatives and Community Engagement

- Shonta leads the development and execution of strategic initiatives to expand PAF's approach to achieve health equity through community and national level partnership engagement and mobilization.
- These initiatives link limited income communities to resources to abate financial, logistical and social access to care barriers.
- 20 years of non-profit and public sector middle and senior level experience that spans public health, women's health and behavioral health.

One Community at a Time

- Strategy: Community engagement and outreach activities

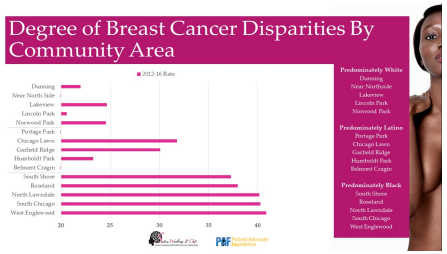
- Goal: To increase awareness and availability of case management services among under-resourced, disparate individuals with chronic, life threatening or debilitating diseases in targeted communities.

- Targeted health conditions or risk factors: Cancer (breast and lung), Cardiovascular disease, Viral hepatitis and Tobacco use

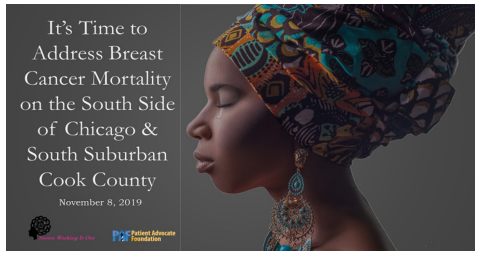
- Communities:
  - Memphis, Tenn.
  - Houston, Texas
  - Chicago, Illinois
  - West Virginia

PAF Community Engagement in Action

Memphis, TN



Howard University-Gynecologic Cancers

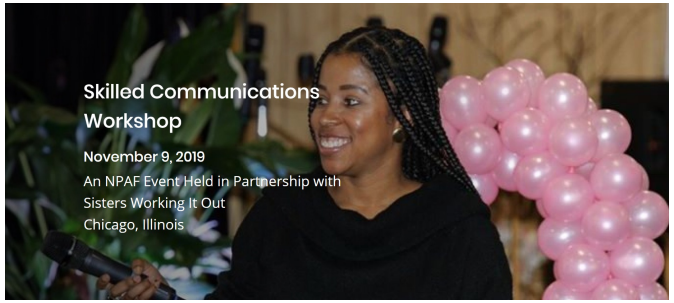


WV LUNG CANCER CareLine

Austin, Texas-Young Survival Coalition

HARLEM

Chicago



patientadvocate.org

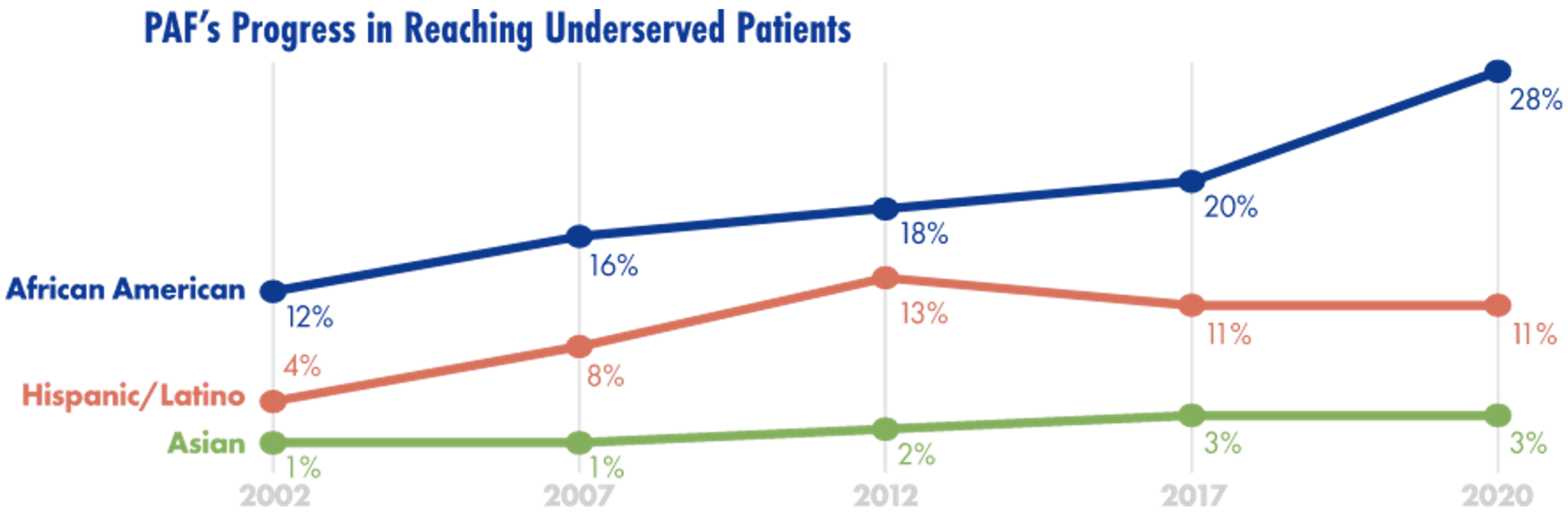
PAF Patient Advocate Foundation

Expanded local partnership engagement

Chicago Chapter

Health Equity & Community Engagement

Since inception, PAF's work has focused on addressing health inequities driven by our service to specific populations experiencing high premature mortality in part because of social determinants of health, or, more specifically, the gaps caused by them.



PAF Health Equity Accomplishments

>1,750

Patients and caregivers reached through three innovative, collaborative outreach events focused on breast cancer with topics ranging from breast cancer screening and treatment to financial resources and PAF services.

10k

Estimated viewers reached with lymphedema educational video produced in partnership with Live Today Foundation

Through SelfMade Health Network, collaborated with the Memphis Breast Care Consortium for video production to educate Black women on what it means to have a breast cancer diagnosis

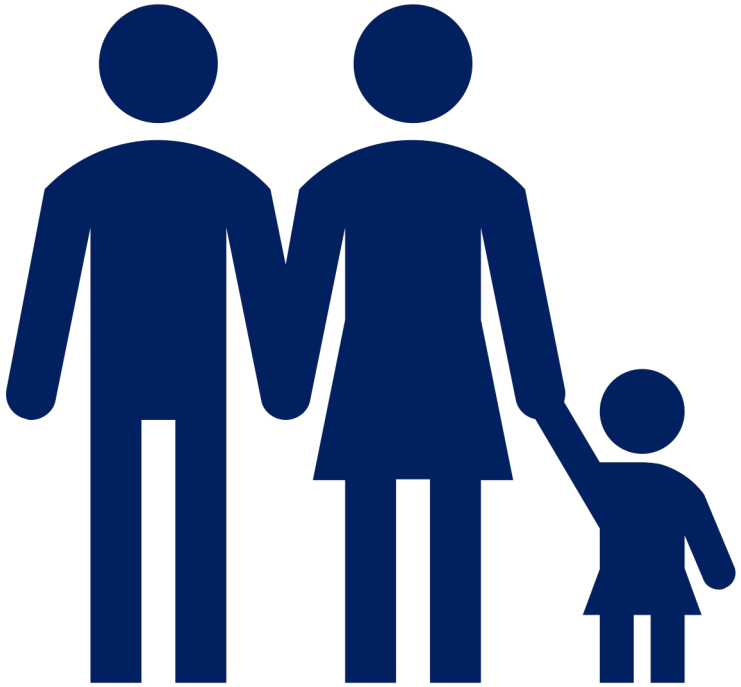
Case Management: What We Help With

Reducing Financial Burden

Enrollment into Appropriate Insurance, Charity and Social Programs

Providing Insurance Navigation

PAF Case Management Patients: A Profile in Courage



51% aged 56+

47% living at our below 250% of FPG

66% are female

89% are insured

40% are from a racial minority group

Top diagnoses included Cancer, COVID-19, Diabetes, Cardiovascular diseases and MS

Top PAF Patient Needs in 2021

Help with healthcare costs

Help paying for utilities

Help paying for housing

Help with transportation

Help with nutritional needs

Help enrolling in disability

Help enrolling in insurance

Figure 1

Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education		Stress	
Support	Walkability				
	Zip code / geography				

Health Outcomes

Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

KFF
HENRY J KAISER FAMILY FOUNDATION

PAF Health Equity Version 2.0

(FY 2020 – current)

CDC's HEALTH EQUITY SCIENCE AND INTERVENTION STRATEGY

C **CULTIVATE Comprehensive health equity science**

CDC will embed health equity principles in the design, implementation, and evaluation of its research, data, surveillance, and interventions strategies.

O **OPTIMIZE interventions**

CDC will use scientific, innovative and data-driven intervention strategies that address environmental, place-based, occupational, policy and systemic factors that impact health outcomes and address drivers of health disparities.

R **REINFORCE and expand robust partnerships**

CDC will seek out and strengthen sustainable multi-level, multi-sectoral and community partnerships to advance health equity.

E **ENHANCE capacity and workforce engagement**

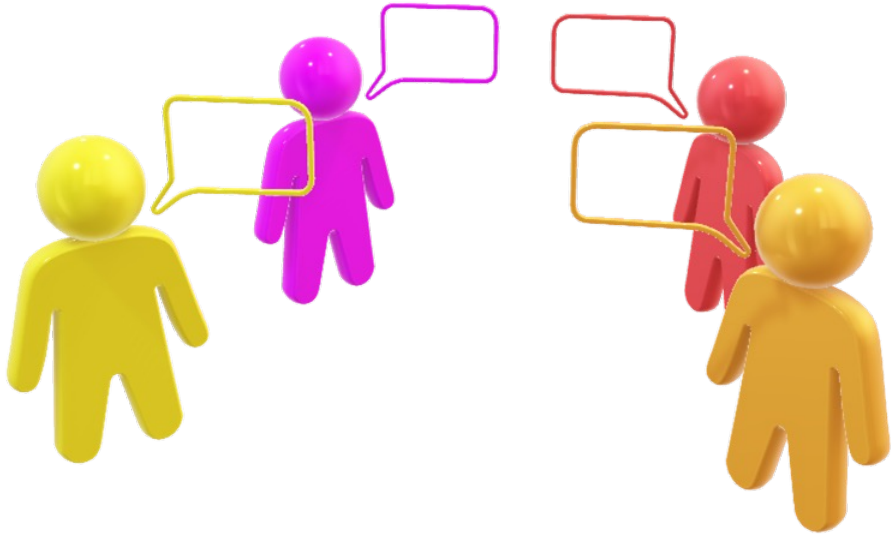
CDC will build internal capacity to cultivate a multi-disciplinary workforce and more inclusive climates, policies, and practices for broader public health impact.

Equity Learning Lab designed to generate evidence to support organizations in their mission to internally center equity, which will enable them to drive equity more effectively in their external work.

Lead: Non-Management Staff
Co-Lead: EVP Health Equity

- Consist of 13-15 members
- Inform organizational priorities related to addressing health equity
- Strategize how PAF can move towards equity (internal and external)
- Meets quarterly to review organizational progress towards equity goals/benchmarks
- Provide input into PAF organizational policies and procedures related to equity
- Forum for ongoing, bi-directional communications with Executive Leadership and staff

PAF/NPAF Health Equity Affinity Group



Patient Advocate Foundation

Our Mission

Patient Advocate Foundation (PAF) is a national 501(c)3 non-profit organization which provides case management services and financial aid to Americans with chronic, life-threatening and debilitating illnesses.

25TH ANNIVERSARY

PROGRAMS AND SERVICES

Direct Patient Services

- CASE MANAGEMENT
- FINANCIAL ASSISTANCE FUNDS
- CO-PAY RELIEF PROGRAM
- HEALTH EQUITY & COMMUNITY ENGAGEMENT
- PATIENT IMPACT
- SPECIAL EVENTS
- HEALTH SERVICES, RESEARCH, PATIENT EXPERIENCE & EVALUATION
- PATIENT EDUCATION & EMPOWERMENT

Outreach

CDC's HEALTH EQUITY SCIENCE AND INTERVENTION STRATEGY

C **CULTIVATE Comprehensive health equity science**

CDC will embed health equity principles in the design, implementation, and evaluation of its research, data, surveillance, and interventions strategies.

O **OPTIMIZE interventions**

CDC will use scientific, innovative and data-driven intervention strategies that address environmental, place-based, occupational, policy and systemic factors that impact health outcomes and address drivers of health disparities.

R **REINFORCE and expand robust partnerships**

CDC will seek out and strengthen sustainable multi-level, multi-sectoral and community partnerships to advance health equity.

E **ENHANCE capacity and workforce engagement**

CDC will build internal capacity to cultivate a multi-disciplinary workforce and more inclusive climates, policies, and practices for broader public health impact.

Health Equity through Community Engagement

We want to further expand our reach into the communities that continue to experience healthcare inequities as we know that there is still much work to do.

Our experience has taught us that the **path to equity and access is through interconnectedness**.

"We can reduce health disparities and better connect people to high-quality medical care, but to really make a difference, we need to address the social determinants of health and equity that protect some people and push others off the cliff."

- Camara Phyllis Jones, MD, MPH, PhD

Call to Action from the CDC

- In November of 2020, the CDC expanded the U.S. Diabetes Surveillance System with a new social determinants of health (SDOH) module to help identify under-resourced areas of the United States.
- We hope that this new tool helps researchers and public health professionals identify and better align available resources to address the needs of people at risk….”
- The social vulnerability index (SVI) helps to identify communities with limited resources.
- Research shows that interventions that improve socio-environmental conditions can lead to better health and reduce health disparities.

Social Vulnerability Index

The social vulnerability index (SVI) helps to identify communities with limited resources.

Four central themes and 15 variables:

- **Socioeconomic status:** below poverty, unemployed, income, no high school diploma
- **Household composition and disability:** persons over age 65, persons under age 17, persons over age 5 with a disability, single-parent households
- **Race/ethnicity and language:** minority status, ability to speak English "less than well"
- **Housing or transportation status:** multi-unit structures, mobile homes, crowding, no vehicle ownership, group living quarters

- "We hope that this new tool helps researchers and public health professionals identify and better align available resources to address the needs of people at risk…."

Identifying Counties with Highest Social Needs

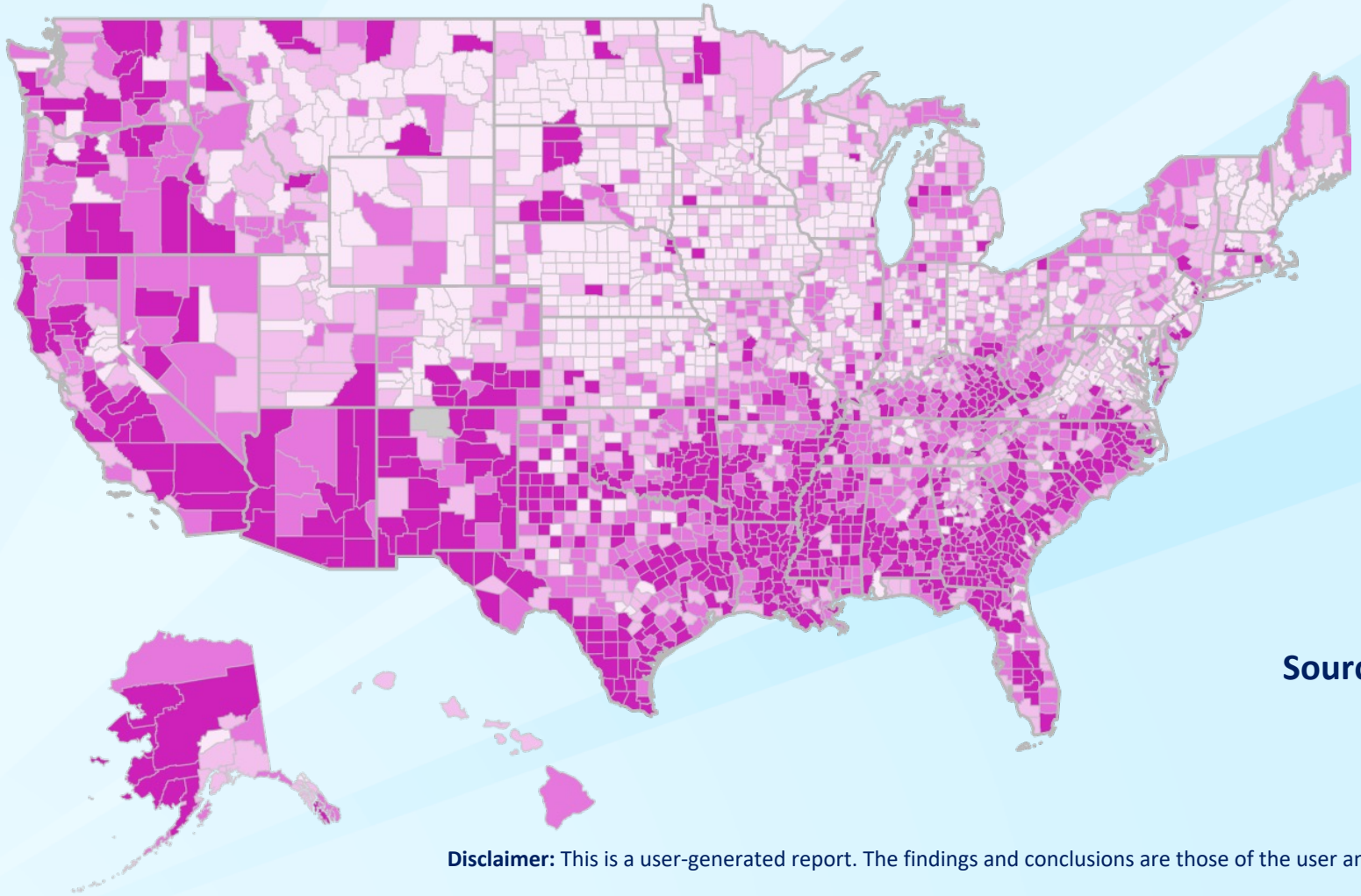
- The social vulnerability index (SVI) helps to identify communities with limited resources.

- The SVI index is 15 variables spanning 4 themes.
  - Socioeconomic status
  - Household composition and disability
  - Race/ethnicity and language
  - Housing or transportation status

- Similarly, PAF created a chronic disease index spanning 17 variables in 4 disease areas
  - Diabetes prevalence
  - Cancer incidence rates in 5 racial and ethnic groups
  - CVD deaths in 5 racial and ethnic groups
  - HIV prevalence in 6 racial and ethnic groups.

  - Cut points based on CDC established breaks for each category.
  - Index score is the summation of all categories in which the county met or exceeded a CDC cut point

SVI Theme: Overall SVI; SVI Variable: Overall SVI; Natural Breaks; Year: 2018

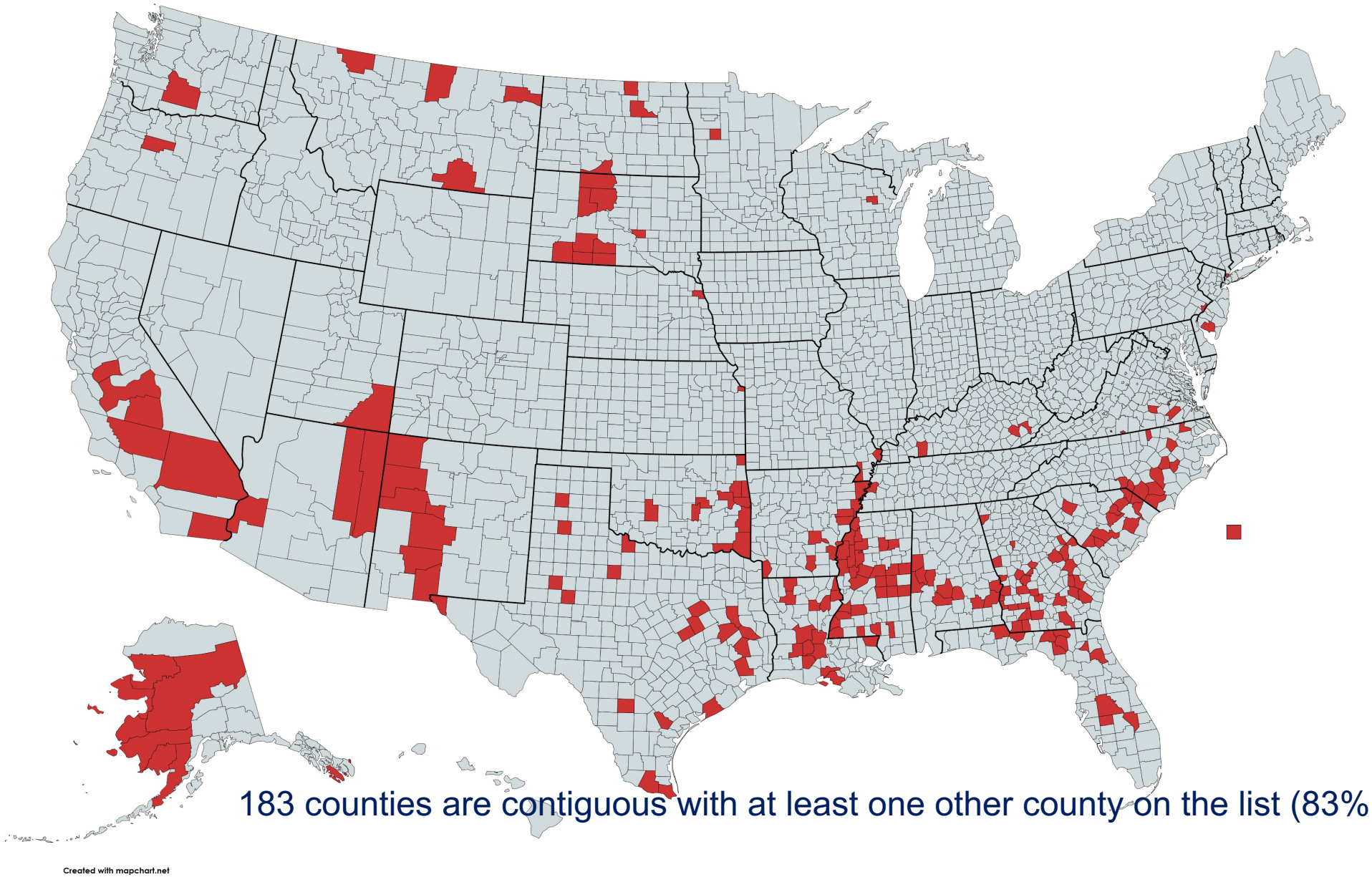


Source: www.cdc.gov/diabetes/data

Disclaimer: This is a user-generated report. The findings and conclusions are those of the user and do not necessarily represent the views of the CDC.

Identifying Counties with Highest Social Needs: Outcome

220 counties have been identified as priority areas



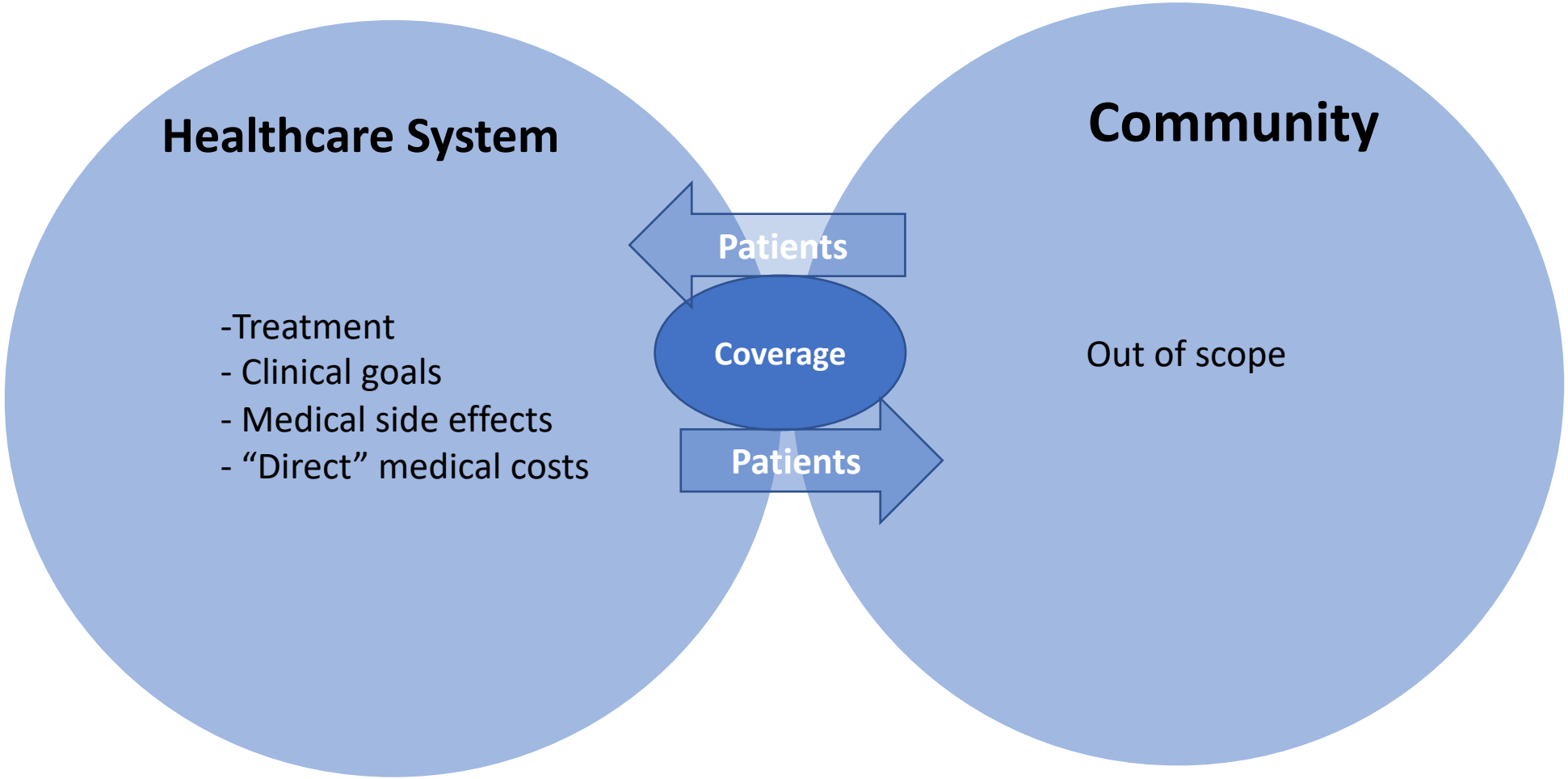
183 counties are contiguous with at least one other county on the list (83%)

PAF Co-Pay Relief Program: Available Health Equity Funds

- Breast Cancer
- Coronary Artery Disease
- Diabetes
- Hepatitis C
- Metastatic Colorectal Cancer
- Multiple Myeloma
- Non-Small Cell Lung Cancers
- Ovarian Cancer
- Prostate Cancer
- Virology Testing

- Building out a robust community outreach and engagement strategy.

Current Healthcare Model



We need to think about the patient journey beyond traditional clinical outcomes and think about the outcomes patients experience outside the four walls of the clinic and pharmacy.

Figure 1

Social Determinants of Health

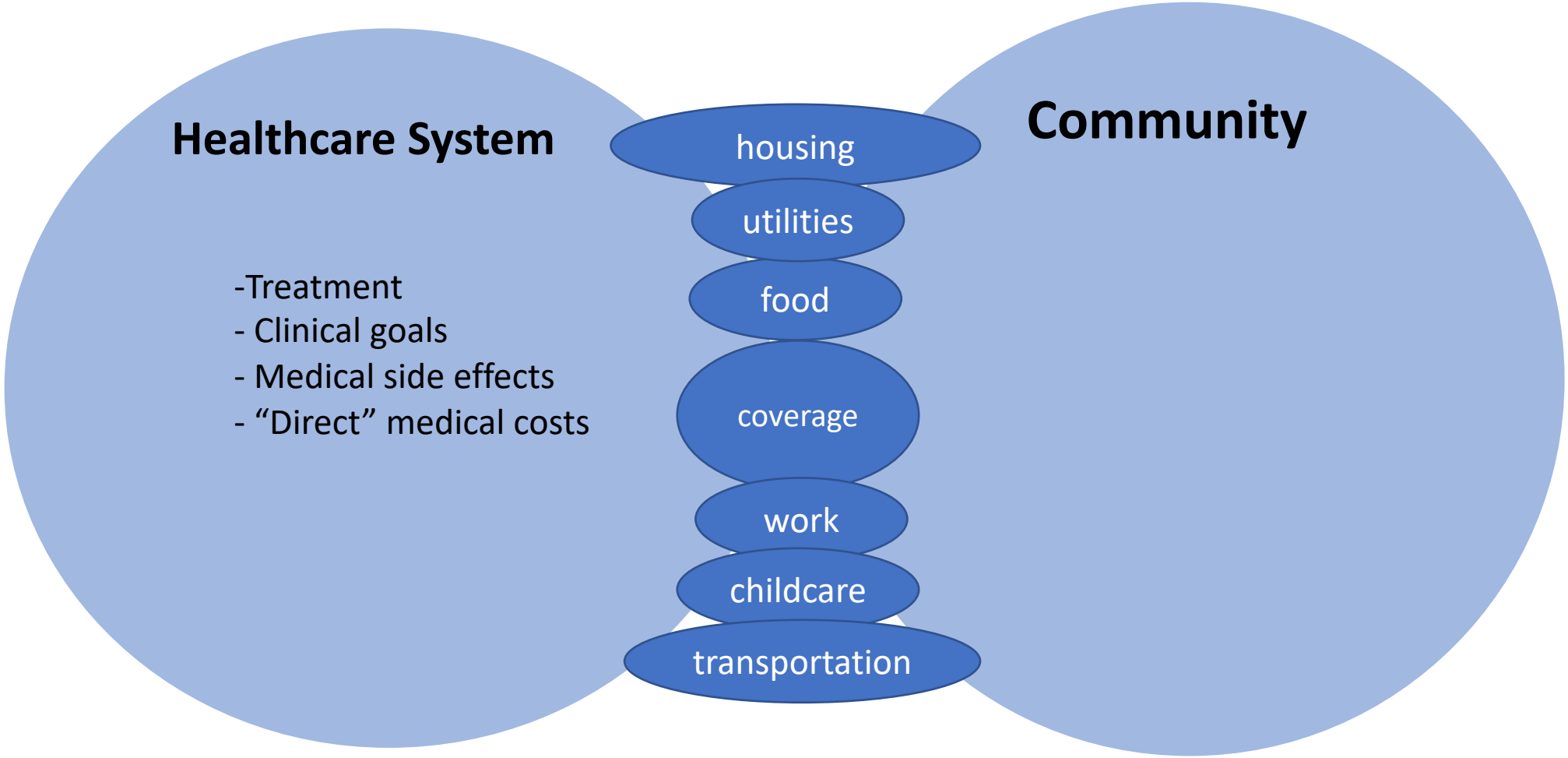
Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education		Stress	
Support	Walkability				
	Zip code / geography				

Health Outcomes

Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

KFF
HENRY J KAISER FAMILY FOUNDATION

The Reality of the Lived Experience



One of the biggest health inequities is the extent to which vulnerable patients make sacrifices in many basic necessities in order to pay for or adhere to their treatment.

Introduction to Z codes

- The medical process is comprised of four key features:
  - Screening
  - Diagnosis
  - Intervention
  - Monitoring

- The healthcare system must be able to do all four things in order to internalize a problem set.

- Z codes are a special group of codes provided in ICD-10-CM for the reporting of factors influencing health status and contact with health services.

ICD-10-CM Codes – Z55-Z65

Persons with potential health hazards related to socioeconomic and psychosocial circumstances

- Z55 Problems related to education and literacy
- Z56 Problems related to employment and unemployment
- Z57 Occupational exposure to risk factors
- Z59 Problems related to housing and economic circumstances
- Z60 Problems related to social environment
- Z62 Problems related to upbringing
- Z63 Other problems related to primary support group, including family circumstances
- Z64 Problems related to certain psychosocial circumstances
- Z65 Problems related to other psychosocial circumstances

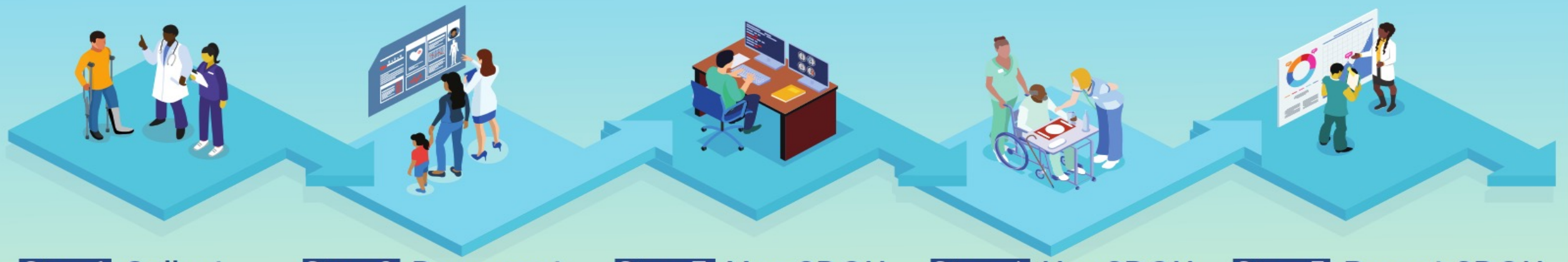
USING Z CODES:

The **Social Determinants of Health (SDOH)** Data Journey to Better Outcomes

What are Z codes

SDOH-related Z codes ranging from Z55-Z65 are the ICD-10-CM encounter reason codes used to document SDOH data (e.g., housing, food insecurity, transportation, etc.).

SDOH are the conditions in the environments where people are born, live, learn, work, play, and age.



Step 1 Collect SDOH Data

Any member of a person's care team can collect SDOH data during any encounter.

- Includes providers, social workers, community health workers, case managers, patient navigators, and nurses.
- Can be collected at intake through health risk assessments, screening tools, person-provider interaction, and individual self-reporting.

Step 2 Document SDOH Data

Data are recorded in a person's paper or electronic health record (EHR).

- SDOH data may be documented in the problem or diagnosis list, patient or client history, or provider notes.
- Care teams may collect more detailed SDOH data than current Z codes allow. These data should be retained.
- Efforts are ongoing to close Z code gaps and standardize SDOH data.

Step 3 Map SDOH Data to Z Codes

Assistance is available from the ICD-10-CM Official Guidelines for Coding and Reporting.[1]

- Coding, billing, and EHR systems help coders assign standardized codes (e.g., Z codes).
- Coders can assign SDOH Z codes based on self-reported data and/or information documented in an individual's health care record by any member of the care team.[2]

Step 4 Use SDOH Z Code Data

Data analysis can help improve quality, care coordination, and experience of care.

- **Identify individuals'** social risk factors and unmet needs.
- **Inform health care** and services, follow-up, and discharge planning.
- **Trigger referrals** to social services that meet individuals' needs.
- **Track referrals** between providers and social service organizations.

Step 5 Report SDOH Z Code Data Findings

SDOH data can be added to key reports for executive leadership and Boards of Directors to inform value-based care opportunities.

- Findings can be shared with social service organizations, providers, health plans, and consumer/patient advisory boards to identify unmet needs.
- A Disparities Impact Statement can be used to identify opportunities for advancing health equity.

For Questions: Contact the **CMS Health Equity Technical Assistance Program**

[1] cms.gov/medicare/icd-10/2021-icd-10-cm
[2] aha.org/system/files/2018-04/value-initiative-icd-10-code-social-determinants-of-health.pdf

Z-code Expansion Efforts

Z59 Expansion: Problems related to housing and economic circumstances

- Z59.41 Lack of adequate food
- Z59.42 Food insecurity
- Z59.43 Lack of safe drinking water
- Z59.61 Unable to pay for prescriptions
- Z59.62 Unable to pay for utilities
- Z59.63 Unable to pay for medical care
- Z59.64 Unable to pay for transportation for medical appointments or prescriptions
- Z59.65 Unable to pay for phone
- Z59.66 Unable to pay for adequate clothing
- Z59.67 Unable to find or pay for childcare
- Z59.69 Unable to pay for other needed items
- Z59.91 Worried about losing housing

Screening + Diagnosis = Intervention

- The medical process is comprised of four key features:
  - Screening
  - Diagnosis
  - Intervention
  - Monitoring

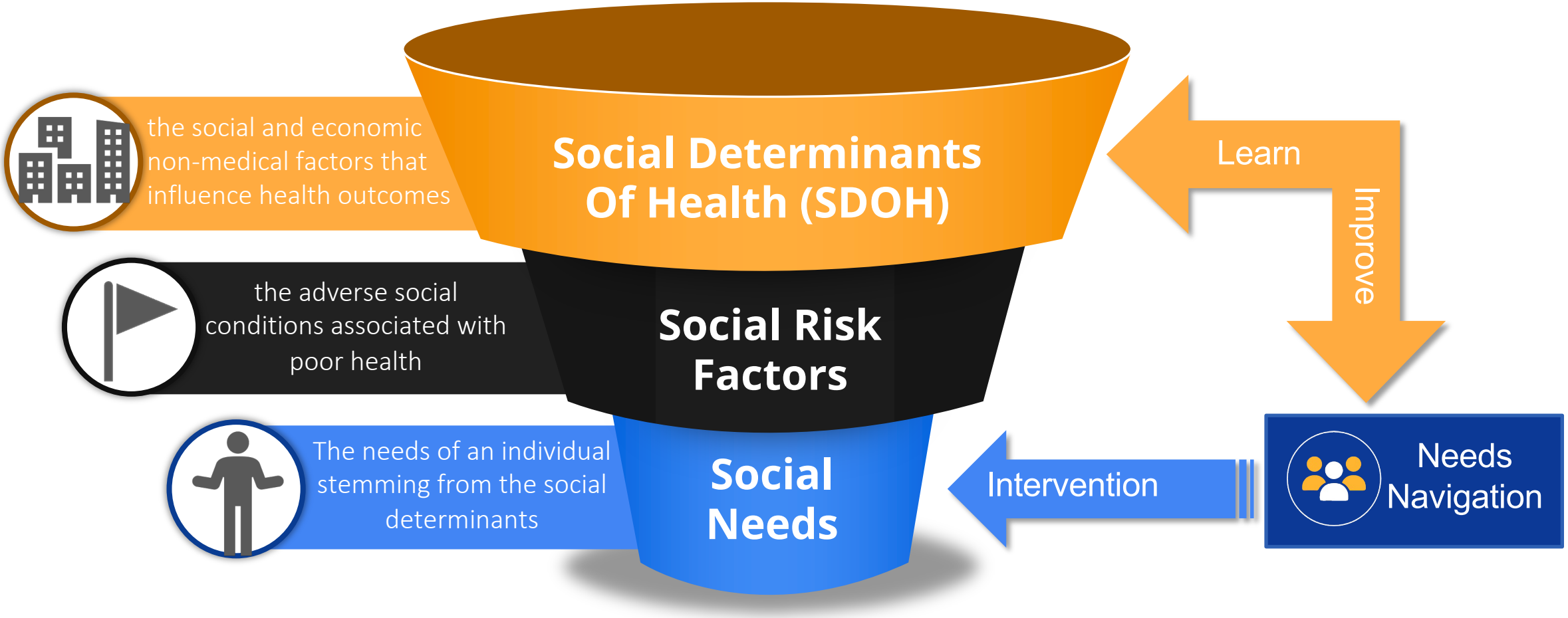
- The healthcare system must be able to do all four things in order to internalize a problem set.

- With diagnosis comes an obligation to intervene.

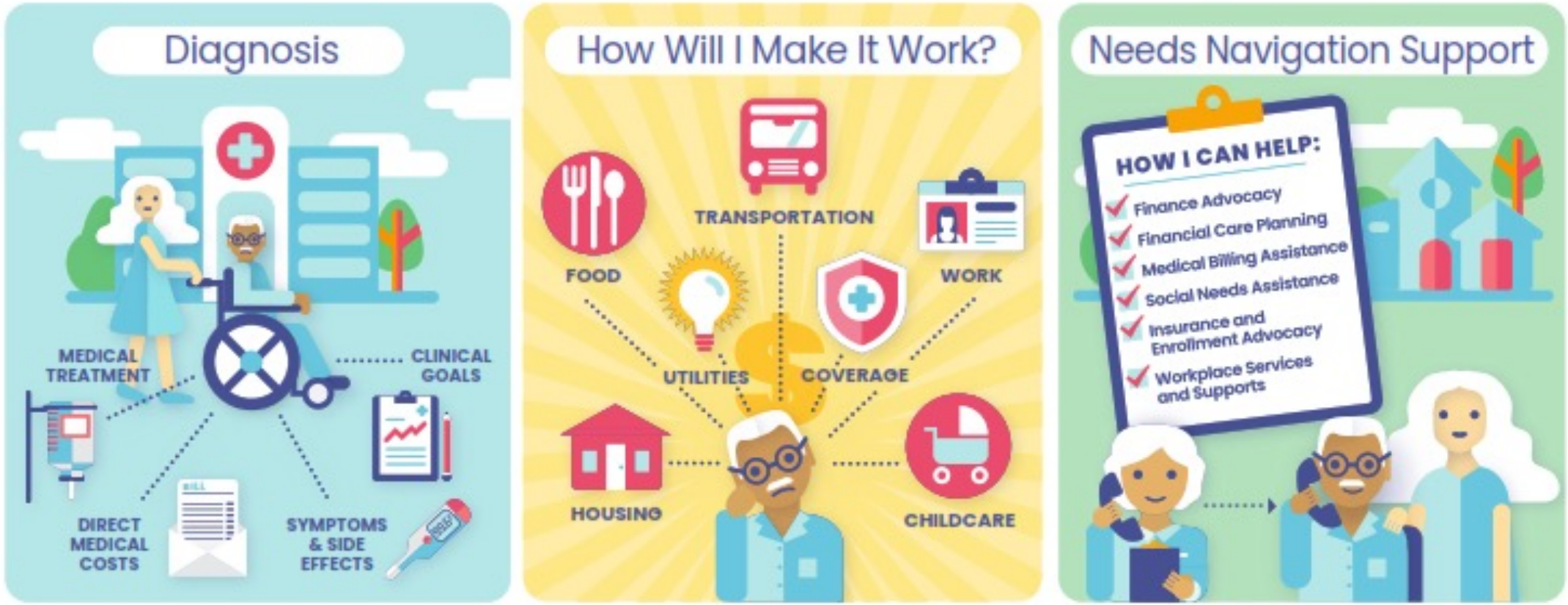
- However, most problems related to social determinants require solutions that can beyond the four walls of the clinic/hospital and require support by external actors.

- The solution is social needs navigation

Moving Beyond #SDOH



THE SOLUTION: Needs Navigation is a Lifeline for Patients and their Families



Findings from a robust National Patient Advocate Foundation (NPAF) environmental scan in 2020 revealed six domains (depicted above) as key features of providing high quality needs navigation services.

Promoting Health Equity and Better Outcomes by Addressing Social Needs

Needs Navigation

Provide people with greater access to resources and the care they need

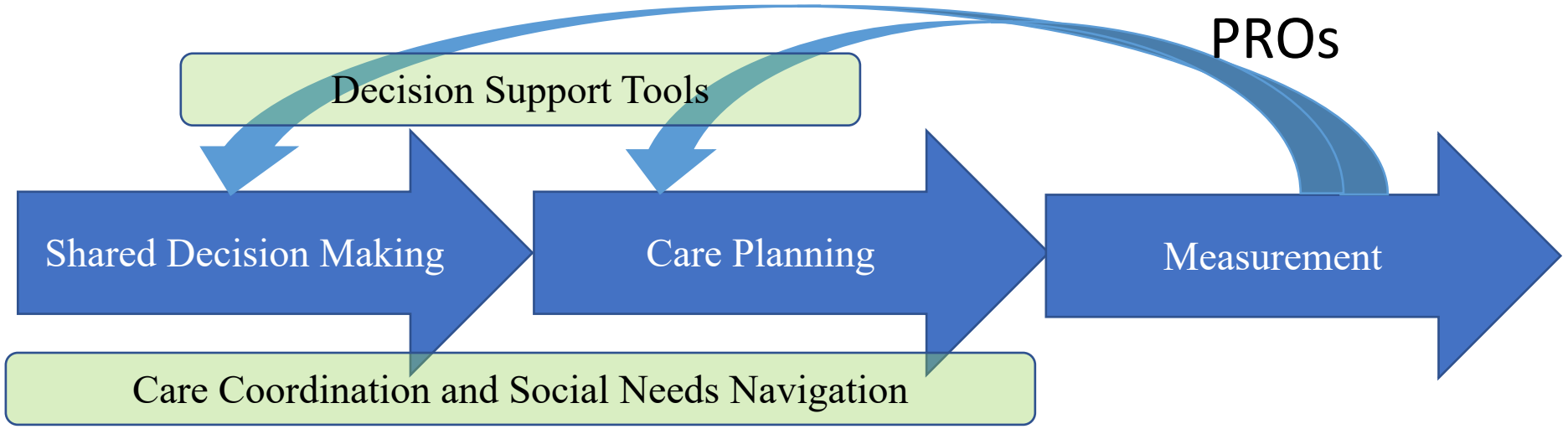
Give us a better understanding the experiences and preferences of patients struggling to navigate and afford healthcare

Inform policies that can help patients and address social risk and SDOH

Ensure research focuses on what is most important to patients

Move us toward a more equitable health system

A Delivery Model for Person-Centered Care



- Expression of personalized goals, needs, and preferences matched against personalized treatment options

Develop a goal concordant care plan that includes identifying social support and care navigation needs

- Data collection and sharing to track adherence and progress
- Patient Reporting on QoL, functional status, health status and safety

Shared Decision Making
and **Care Planning**
are the clinical processes by which to co-create and deliver
Person Centered Care

Respect—seeing and treating each person as an individual, not making assumptions or judgments

Listening—a genuine two-way discussion, not just dictating treatment or "hearing without actually listening."

Personal Connection—wanting a relationship, or to be acknowledged on a personal level by the doctor or provider

ELEMENTS OF PATIENT PROVIDER TRUST

- Trust is an essential component of any interpersonal relationship, but it is particularly integral to the relationship between patients and their physicians
- Patient-physician trust increases willingness to seek treatment, disclose sensitive information, adhere to medical recommendations, and share decision-making authority
- Healthcare as an industry (and as a set of providers) is particularly vulnerable to deficits of trust
- Trust and reputation are important indicators of institutional health at both the provider and facility level

Thank you

PAF 2021 Word Cloud

advocacy CHATS COA Patient Advocacy Network

Thank You to Alan Balch & Our Listeners!

Don't miss our next advocacy chat

Wednesday, May 11, 2022, 12:00 PM – 12:30 PM ET

Clinical Trials in the Community Oncology Setting