

# Let's Listen: Capturing Community Voices in Advance Care Planning Tools

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# Gloria A. Brooks

- Co-Chair, WHI Advanced Care Planning Sub-Committee
- Seventeen years experience in post-acute home health settings
- 9 years as President & CEO of Arbor Hospice & Palliative Care
- Led development of community-based palliative care program Currently serves as VP Chief Strategy Officer for Arbor Hospice & Hospice of Michigan
- Leads statewide service line development for advanced illness and end of life continuum of care services incorporating virtual models of care

# Dr. Genevieve Stewart

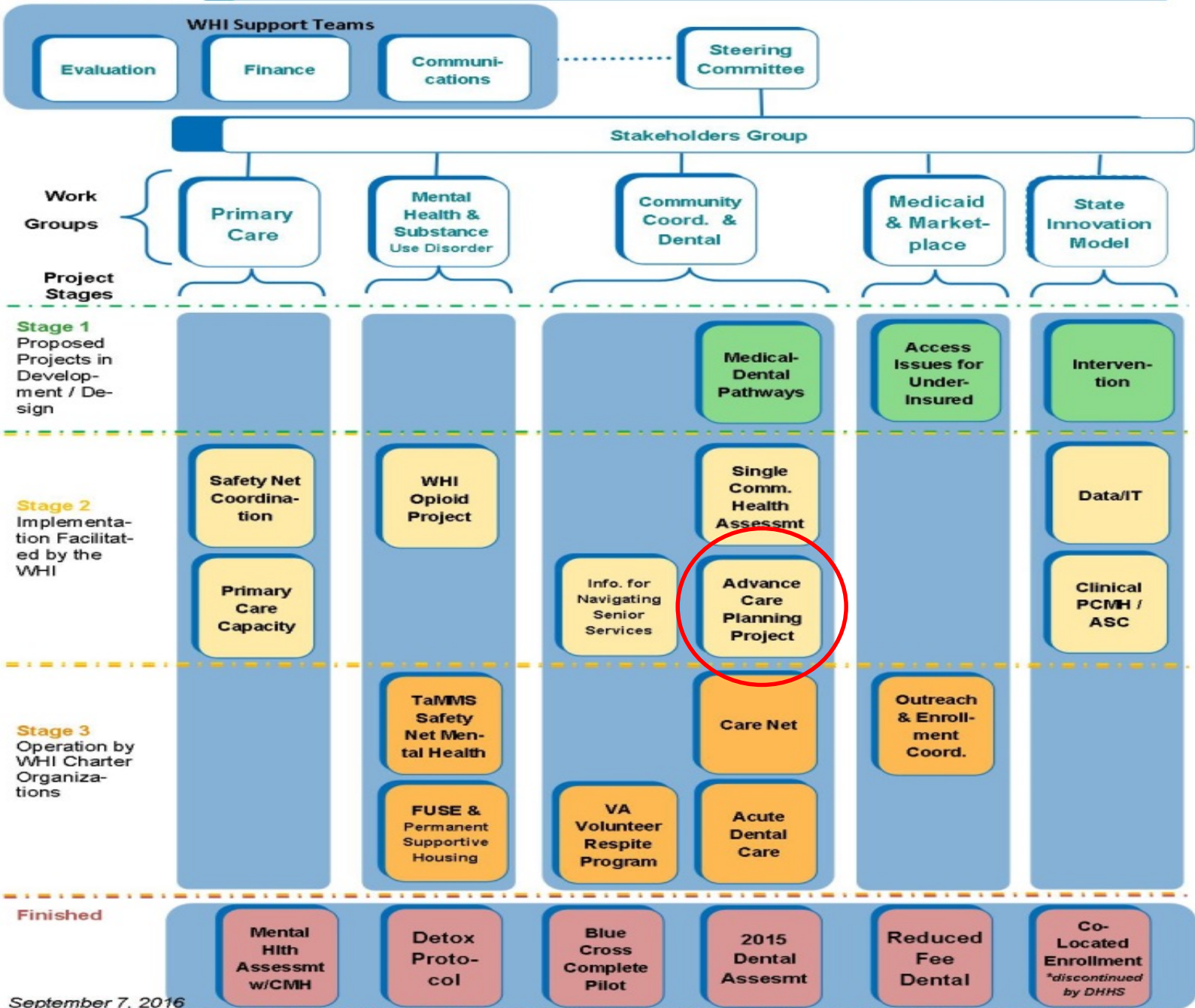
- Medical Director, St. Joseph Mercy Hospital Palliative Care Program
- Palliative Care physician practicing in both inpatient and outpatient settings
- Member of Washtenaw Health Initiative Advance Care Planning Sub-committee
- Research interests include use of risk stratification tools to generate early palliative care consultation
- Fifteen years experience as an academic hospitalist

# Objectives

Understand the importance of incorporating community driven perspectives into developing tools.

Explain the process of incorporating community voices into developing tools.

Discuss how to integrate community-level perspectives into future work.



## Goal

- To improve the quality of life for Washtenaw County residents so when they face a serious illness, their preferences are known and respected

## Charge

- Promote a more patient-centered approach to delivering advance care planning by:
  - Engaging community members to identify gaps in care and determine best practices.
  - Educating providers and community members on the steps involved in advance care planning and providing tools to support the various processes.
  - Recommending a standardized process for advance care planning across all healthcare providers and settings.

# Defining the Problem



Advance Care Planning (ACP) has been shown to increase a patient's comfort at the end of life, yet participation remains low.

**National Poll:** 89% of the public said they'd feel very comfortable talking about end-of-life wishes with their spouse or partner. Only 17% said that they had a discussion with their doctor.

It is important to have conversations with family members about, one's wishes, beliefs, and goals for their care and quality of life.

# Focus Groups Overview

Washtenaw Health Initiative's ACP project members conducted a series of focus groups and interviews with over 80 Washtenaw County community members and physicians to better understand the experiences and challenges to ACP.

## Consumer Focus Groups

Huron Valley PACE, Veterans, African Americans, Rural Population

## Healthcare Provider Focus Groups

University of Michigan Health System and Saint Joseph Mercy Health System

## Outpatient Provider Interviews

Providers in geriatrics, internal and family medicine, sub-acute rehabilitation, and long-term care



## Consumers

- Provided a list of Advance Care Planning terms, asked about familiarity and recognition
- Asked about reasons for completing and Advance Directive (AD) or not completing and AD.
- Asked for general advice to make it easier to have Advance Care Planning Conversations.

## Providers

- Provided a list of Advance Care Planning terms, asked about familiarity and recognition
- Asked “what are the Key elements of an Advance Care Planning Conversation?”
- Asked for reasons why the conversation is either easy or challenging
- Asked for general advice to make it easier for health care providers to have Advance Care Planning Conversations with their patients.

# Consumer and Providers both worried about...

AD may not be accessible when needed, and how this would lead to treatment that did not follow the patient preferences

Challenges with  
ACP  
Documentation

Challenges with  
the ACP Process  
and Decision  
Making

Too many opinions may complicate medical decision making.

# Consumer Findings

Major  
Themes

Consumer  
Knowledge

Challenges  
and Concerns

Experience  
with ACP

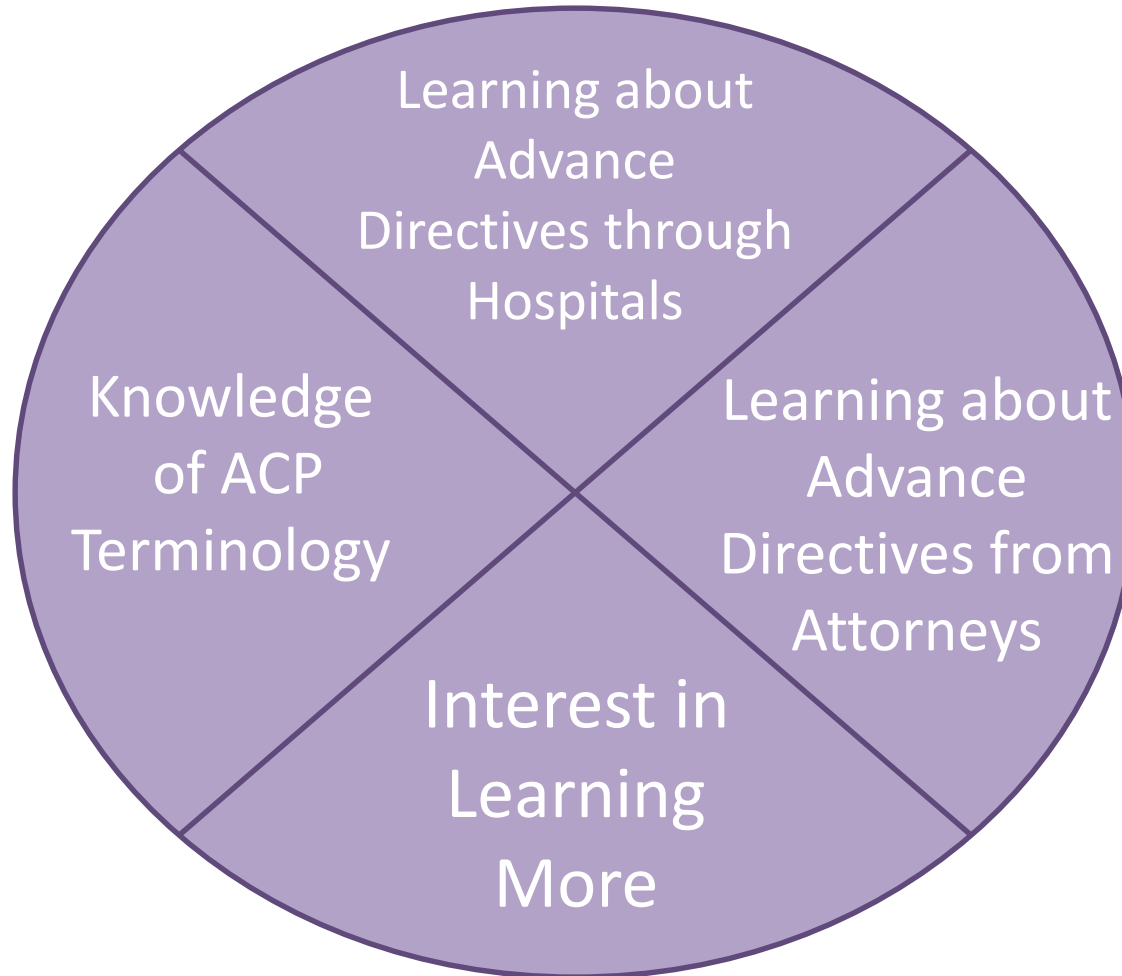
# Major Themes

Fear and  
Uncertainty

Preferences  
will not be  
honored

Confusion  
about  
requirements

# Consumer Knowledge



## Challenges to ACP related to

- emotional barriers
- provider concerns
- documentation
- concerns that treatment preferences would not be honored.

Challenges often depended on whether the group had more or less experience with ACP or had completed an AD

In the African American focus group, many highlighted African Americans' general medical mistrust, due to the negative history with African Americans and medical care in the US, as a major barrier to ACP.

# Experience with ACP

For consumers, concerns about ADs often depended on their level of ACP experience.



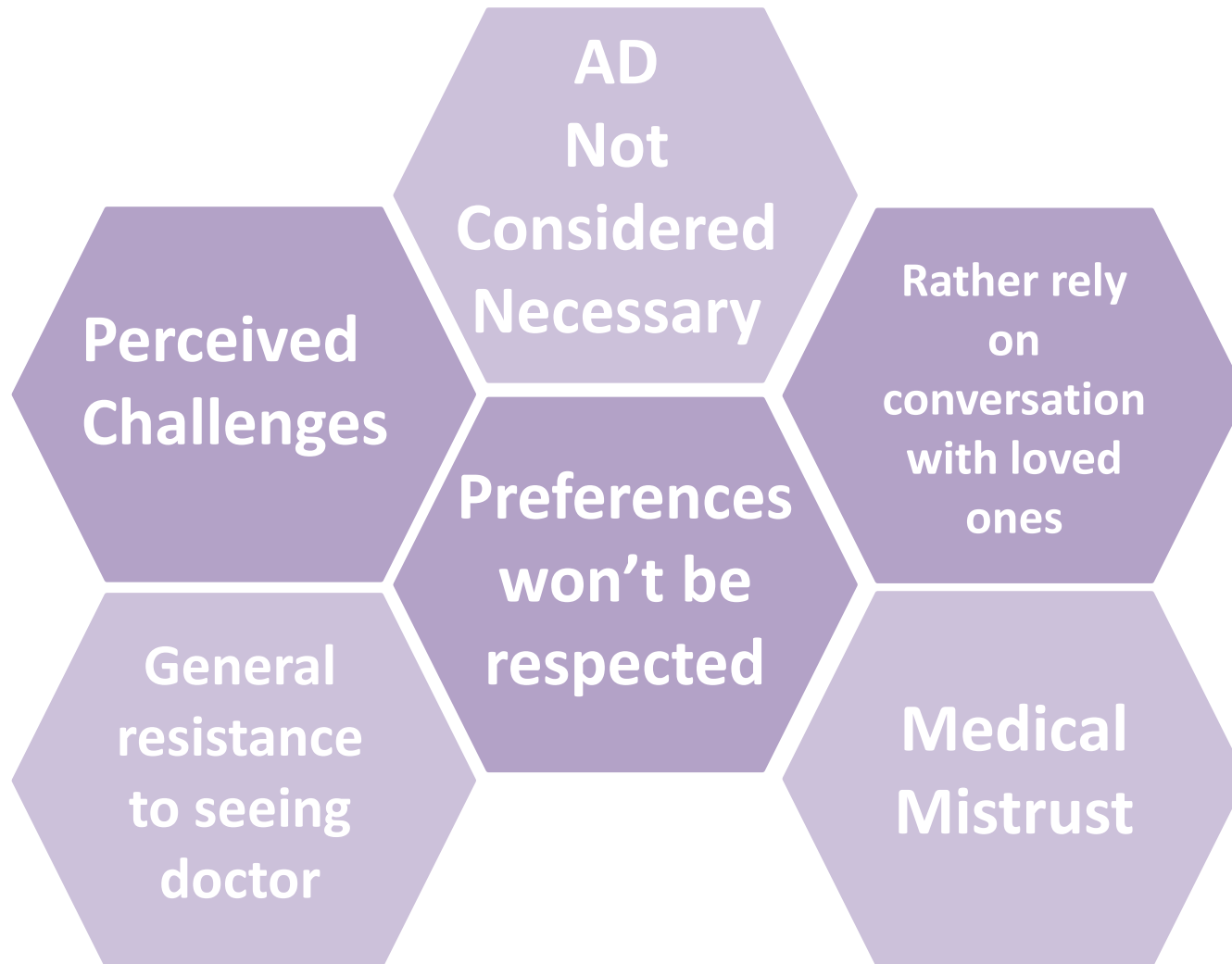
Concern about preferences being honored based on previous experiences



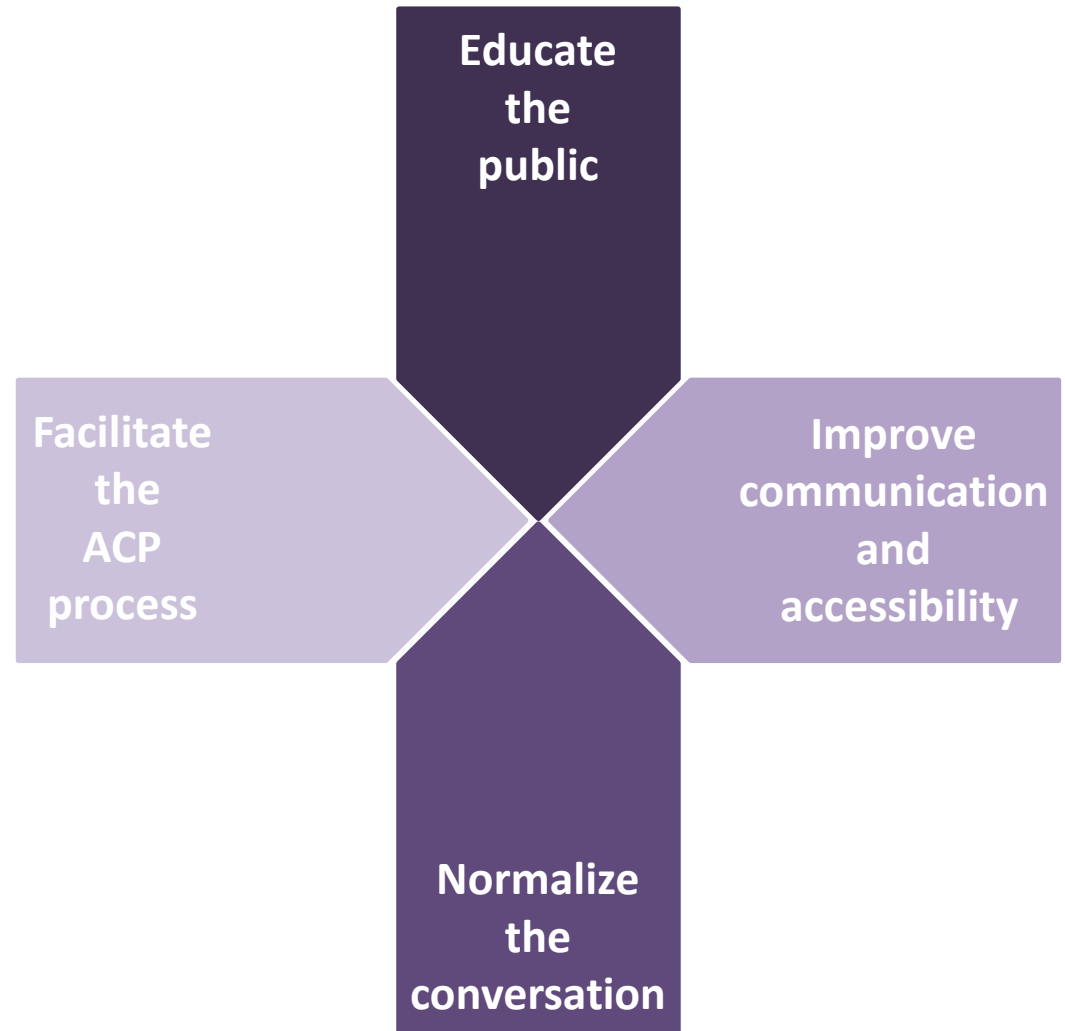
Concern about limiting their treatment options and difficulty of writing wishes down.



# Reasons for Not Completing an Advance Directive



Overall, consumer recommendations fell into **four** categories:



# Healthcare Provider Findings

Major Themes

Experiences and  
Challenges with  
ACP

Training and  
Education

Key Elements to  
ACP

# Major Themes

Lack of  
necessary  
training

Utility of an  
Advance  
Directive

Lack of time

# Experience and Challenges

## Both Inpatient and Outpatient Settings

Type of illness and quality of life

Medical Decision Making

### Inpatient Setting

Documentation and utility of AD

Acuity in the inpatient setting

### Outpatient Setting

Time and comfort

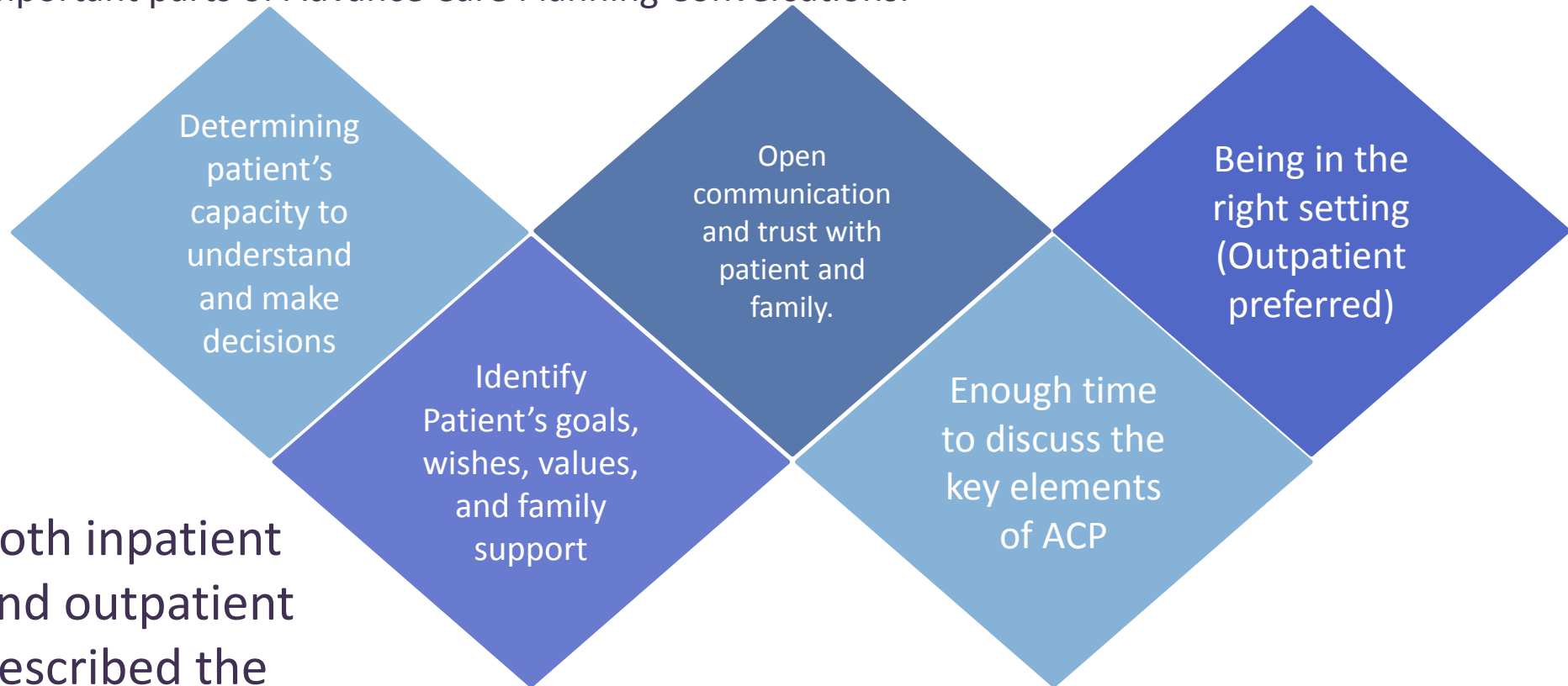
Training, resources, and staff support



Most physicians do not have formal ACP training

Need for resources to facilitate conversations, such as educational materials, guidelines, and staff support.

In the focus groups and interviews, providers discussed what they believe are the most important parts of Advance Care Planning Conversations.



Both inpatient and outpatient described the most important parts of ACP as...



Determining  
the patient's  
prognosis and  
code status

Having the  
support of  
the palliative  
care team

The patient  
has a good  
sense of their  
illness

Having the  
conversation  
with others  
prior to the  
inpatient  
setting

Family and/or  
Patient  
Advocate is  
with them

Inpatient  
providers  
described the  
most important  
parts of ACP as...

Meeting the patient where they are at in terms of comfort and readiness

Making the conversation resonate with the patient

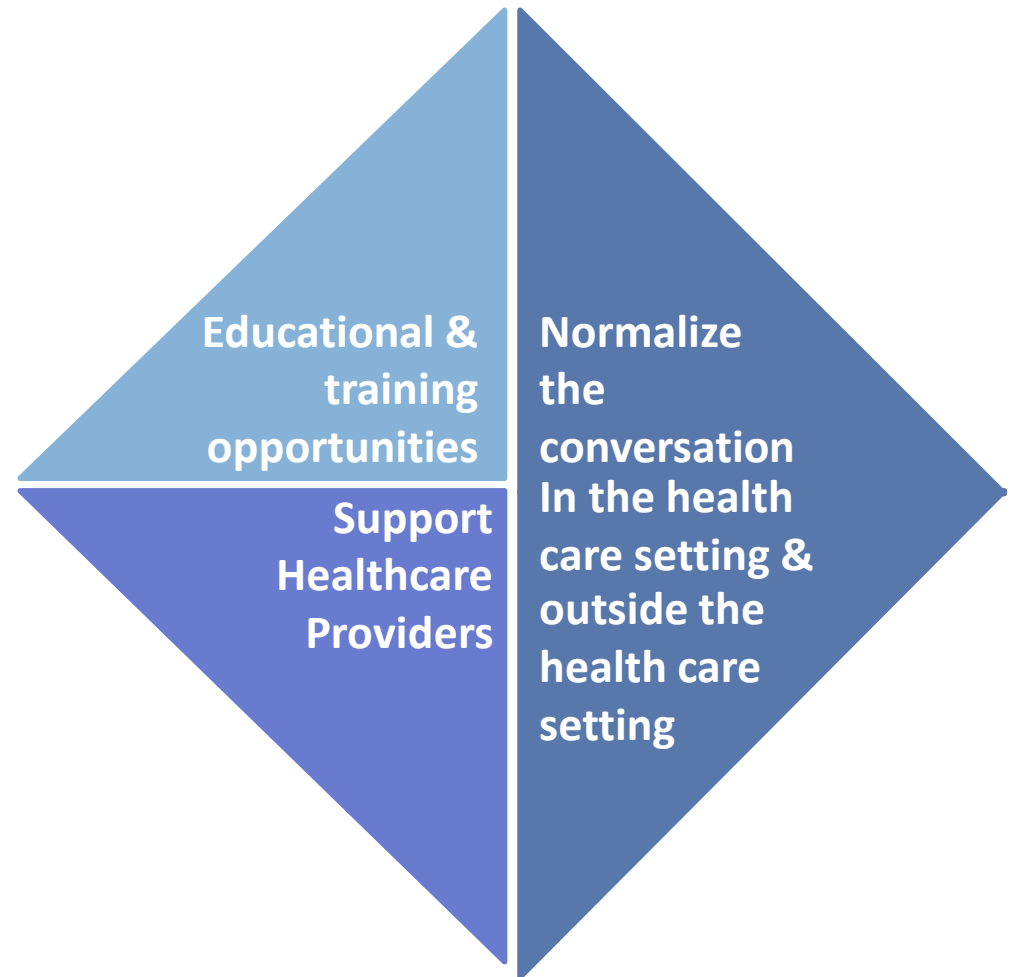
Shaping the conversation around a narrative

Identifying patients comfort with the conversation

Identifying potential barriers to the conversation

Outpatient providers described the most important parts of ACP as...

Providers  
recommendations  
fell into  
**three**  
categories:



The group used this info to standardize the process in the community regarding advanced care planning conversations.

## “Making Your Health Care Wishes Known”

The outcome is a Conversation Guide meant to be used with any advanced care directive.

Examining  
your values

Selecting a  
Patient Advocate



Engaging in a  
conversation with  
your loved ones and  
healthcare providers

Stating and  
documenting your  
wishes for health  
care for the future

In summary, the focus groups revealed important content from both healthcare providers and consumers regarding challenges with Advance Care Planning in our community.

This information will be used to improve awareness and experience with Advance Care Planning in Washtenaw County.

This work is indebted to the time and information generously provided by community members and healthcare providers in Washtenaw County.

# Questions?

# Get involved/Contact Us

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