Advance Care Planning and AI/AN Populations

May 27, 2026

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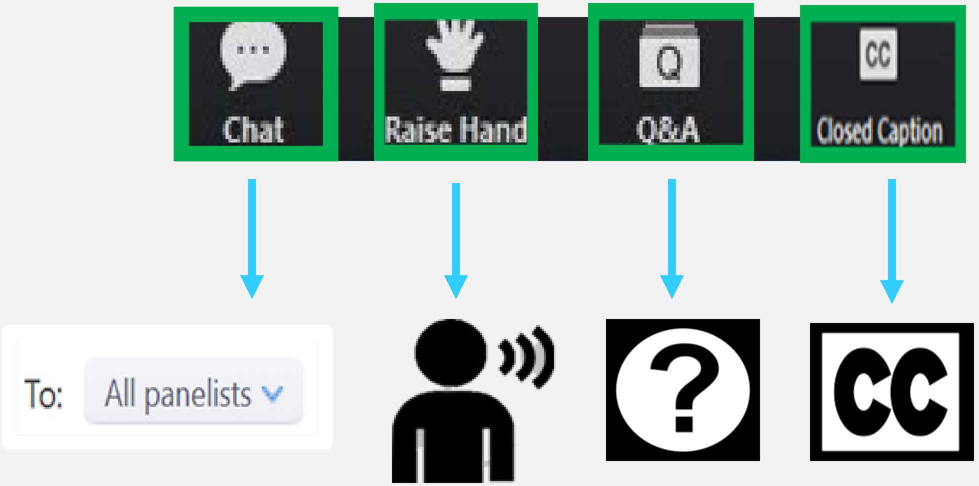

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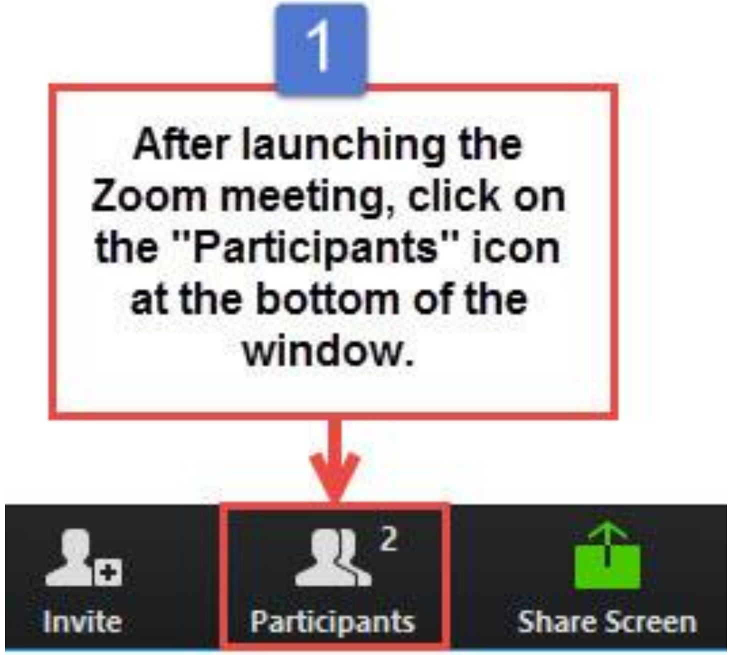

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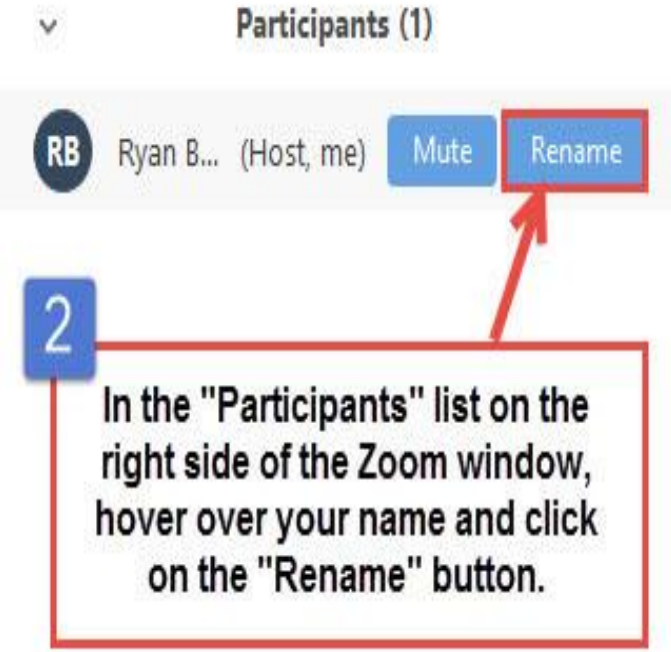

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In the "Participants" list on the right side of the Zoom window, hover over your name and click on the "Rename" button.

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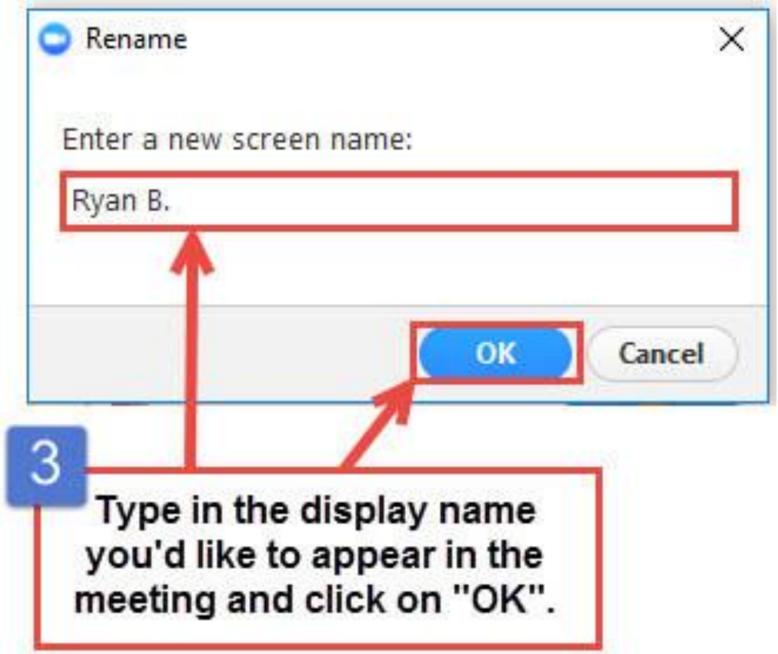
Example: Cary D., VOAD



Enter a new screen name:

Ryan B.

3

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Advance Care Planning and AI/AN Populations

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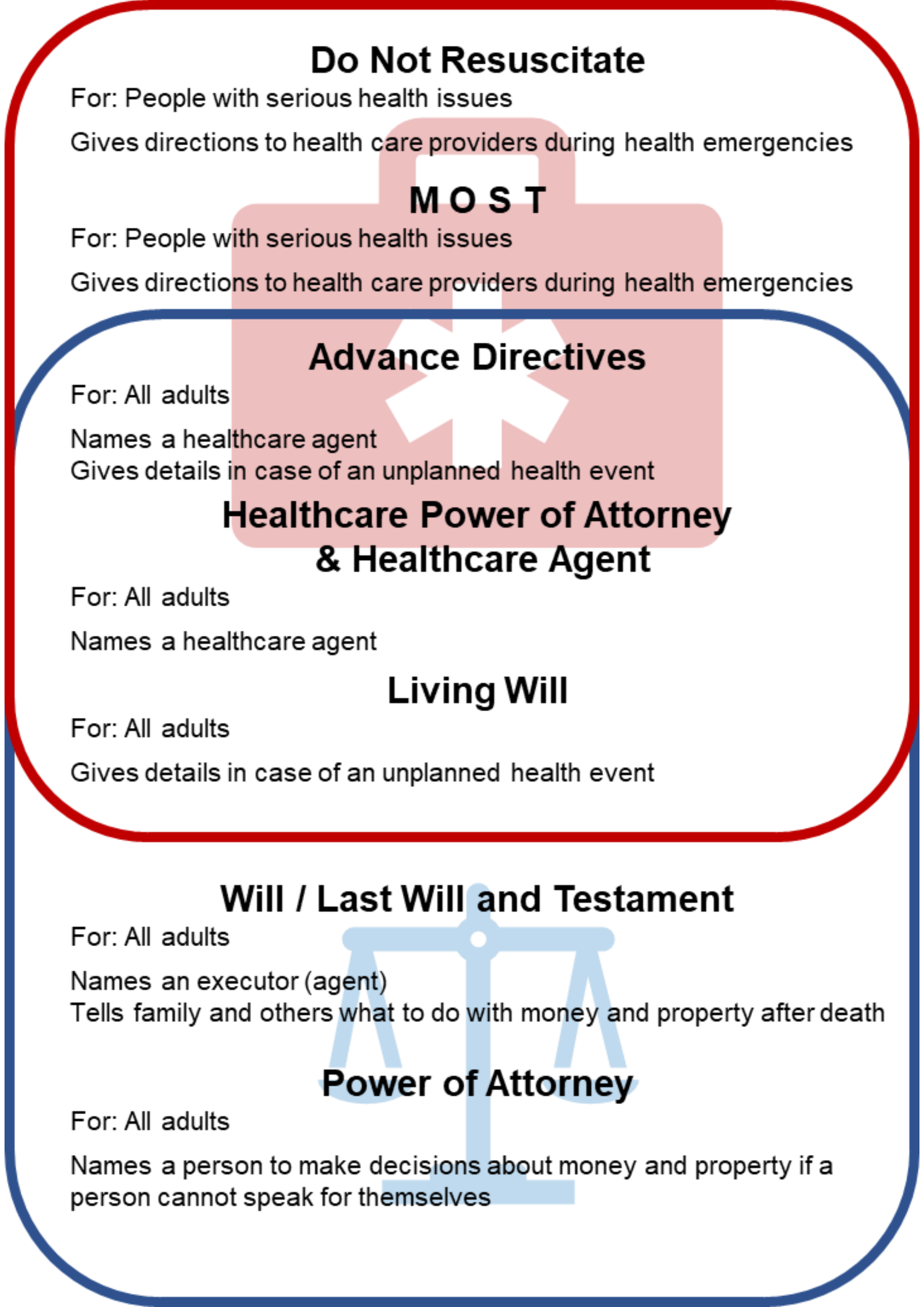
Objectives

- Identify why advance care planning is important for people who work with American Indians and Alaska Natives (AI/ANs)
- State two barriers to advance care planning for AI/ANs
- Describe at least one approach participants can use to culturally tailor advance care planning tools
- Identify at least two resources that may assist with end-of-life conversations

Terminology



Do Not Resuscitate

For: People with serious health issues

Gives directions to health care providers during health emergencies

MOST

For: People with serious health issues

Gives directions to health care providers during health emergencies

Advance Directives

For: All adults

Names a healthcare agent
Gives details in case of an unplanned health event

Healthcare Power of Attorney & Healthcare Agent

For: All adults

Names a healthcare agent

Living Will

For: All adults

Gives details in case of an unplanned health event

Will / Last Will and Testament

For: All adults

Names an executor (agent)
Tells family and others what to do with money and property after death

Power of Attorney

For: All adults

Names a person to make decisions about money and property if a person cannot speak for themselves

- End-of-life care
- Hospice
- Palliative care
- Do not resuscitate
- MOST and POLST
- Advance directives
- Healthcare or medical power of attorney
- Living will
- Will/last will and testament
- Power of attorney

What is Advance Care Planning and Why is It Important?

Importance of Advance Care Planning

Helps Respect Patient Wishes

Ensures that healthcare aligns with the patient’s values and preferences.

Prevents Unnecessary Treatments

Avoids unwanted medical interventions that may not improve quality of life.

Provides Clarity for Family and Providers

Reduces confusion and stress for families and healthcare providers during emergencies.

Promotes Autonomy and Dignity

Empowers individuals to make decisions about their healthcare in advance.

Facilitates Better Healthcare Outcomes

Leads to care that is more consistent with patient’s goals and desires.

Advance Care Planning and American Indians

A study of American Indians and non-Hispanic Whites in two Midwest states[1] found that American Indians were less likely to have:

- An advance care plan
- Living will
- Durable power of attorney

A comparative retrospective analysis of American Indians and non-Hispanic Whites in North Carolina[2] between 2003 and 2018 found American Indians had:

- More hospital admissions
- More ICU admissions
- More than one emergency room visit in the last 30 days of life

1. Kwak et al. (2019). *Research in Gerontological Nursing*, *12*(1), 34–43. https://doi.org/10.3928/19404921-20181212-02
2. Emerson et al. (2025). *JNCI: Journal of the National Cancer Institute*, *117*(6), 1188–1197. https://doi.org/10.1093/jnci/djaf007

Disparities in End-of-Life Care for AI/ANs

A 2019 Medicare study[3] found that AI/AN patients at end of life were:

- **More likely to be hospitalized**
- **Less likely to use hospice services**

Lower hospice use was especially associated with chronic illnesses such as:

- Diabetes
- Cardiovascular disease
- Kidney disease
- Liver disease

[3] Anderson et al. (2025). *Journal of Palliative Medicine*, *28*(9), 1185–1192. https://doi.org/10.1089/jpm.2024.0481

Barriers to Advance Care Planning

Barrier Category	**Description**
Lack of Awareness	Many individuals and families are unaware of advance care planning options and benefits.
Emotional Difficulty	Discussing future health wishes can be emotionally challenging for patients and families.
Cultural Factors	**Cultural beliefs and values can influence attitudes toward end-of-life discussions.**
Healthcare Provider Discomfort	Providers might feel uncomfortable initiating or discussing advance care planning.
Healthcare Provider Beliefs	**Providers could have false beliefs about another culture and that culture’s willingness to engage in end-of-life conversations.**

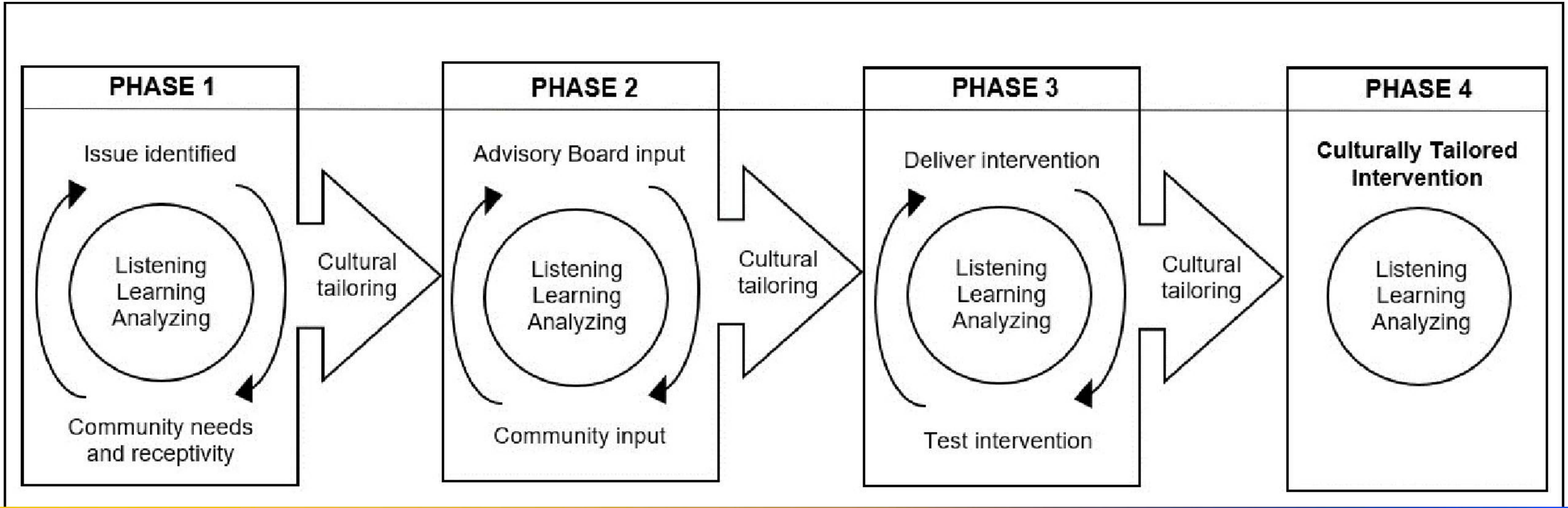
Culturally Tailoring an Advance Care Planning Tool[4]

4. Goins et al. (2024). *Ethnicity & Health, 29*(8), 908–923. https://doi.org/10.1080/13557858.2024.2401830

Culturally Tailoring Advance Care Planning Tools: The MY WAY Study

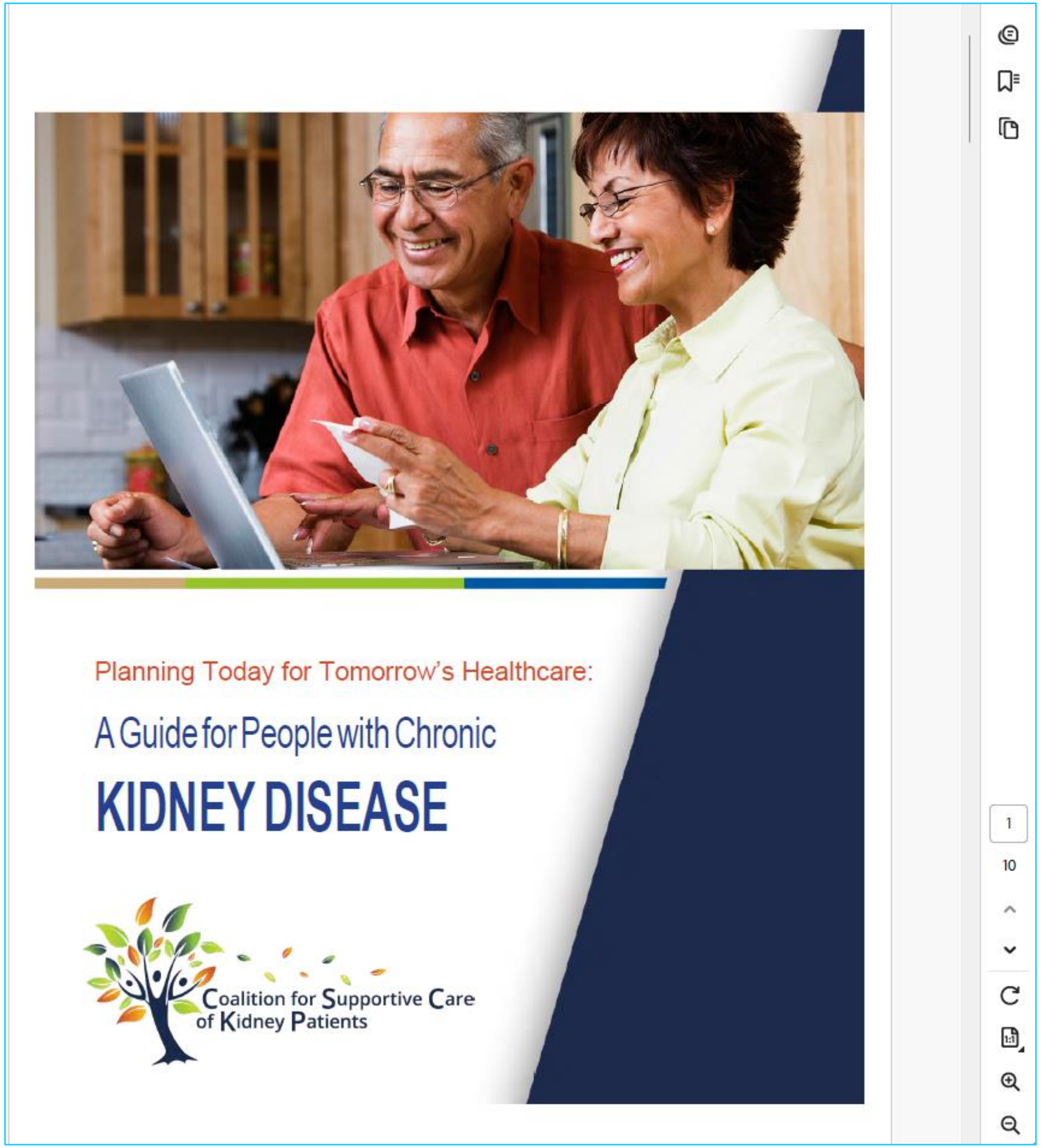
Community-based program to modify an existing advance care planning curriculum:

- Intense community engagement in cultural tailoring that spanned approximately 2 years before we offered the MY WAY program in a focused research study
- Engagement included a community advisory board and professional advisory board



Cultural Tailoring: Not Just About Different Pictures

	Original MY WAY	Culturally Tailored MY WAY
Delivery	Single encounter, a meeting in a clinical setting and instruction delivered by a healthcare provider	Two sequential encounters held in a community setting with a traditional meal and coaching delivered by a Support Star
	No choice of instructional provider	Choice between instruction from tribal member or non-tribal member
Content	For age 55 and up	For age 18 and up
	Focused on chronic kidney disease	All adults, no disease specified
	English only, very text heavy	English, scaled back to essential information with some tribal language included
	Uses clinical language, stock images of people, and generic locations	Focused on region, with local and recognizable people included in images
	10 pages, letter sized	8 pages, bi-fold size

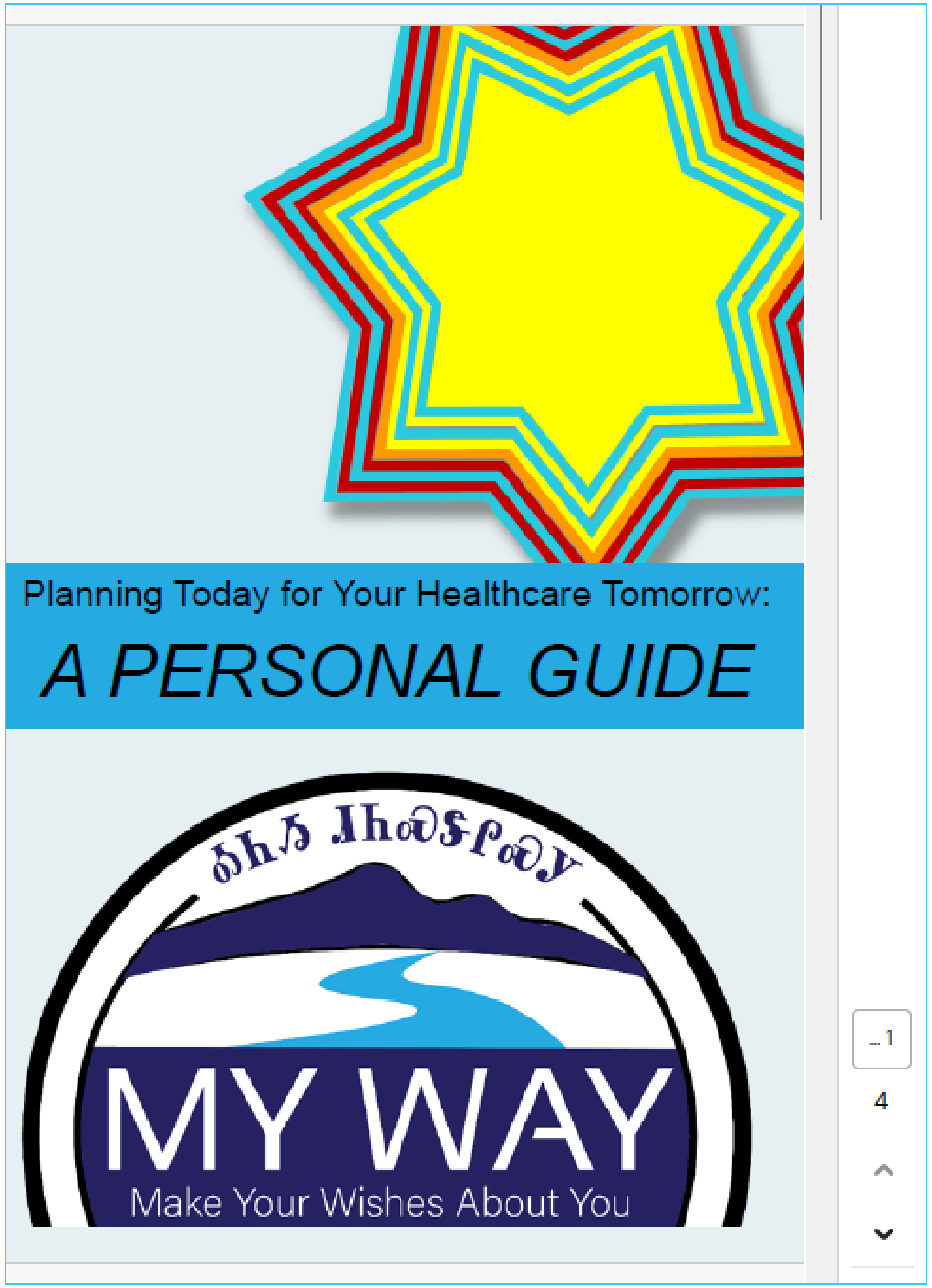


Planning Today for Tomorrow's Healthcare:

A Guide for People with Chronic

KIDNEY DISEASE

Coalition for Supportive Care of Kidney Patients

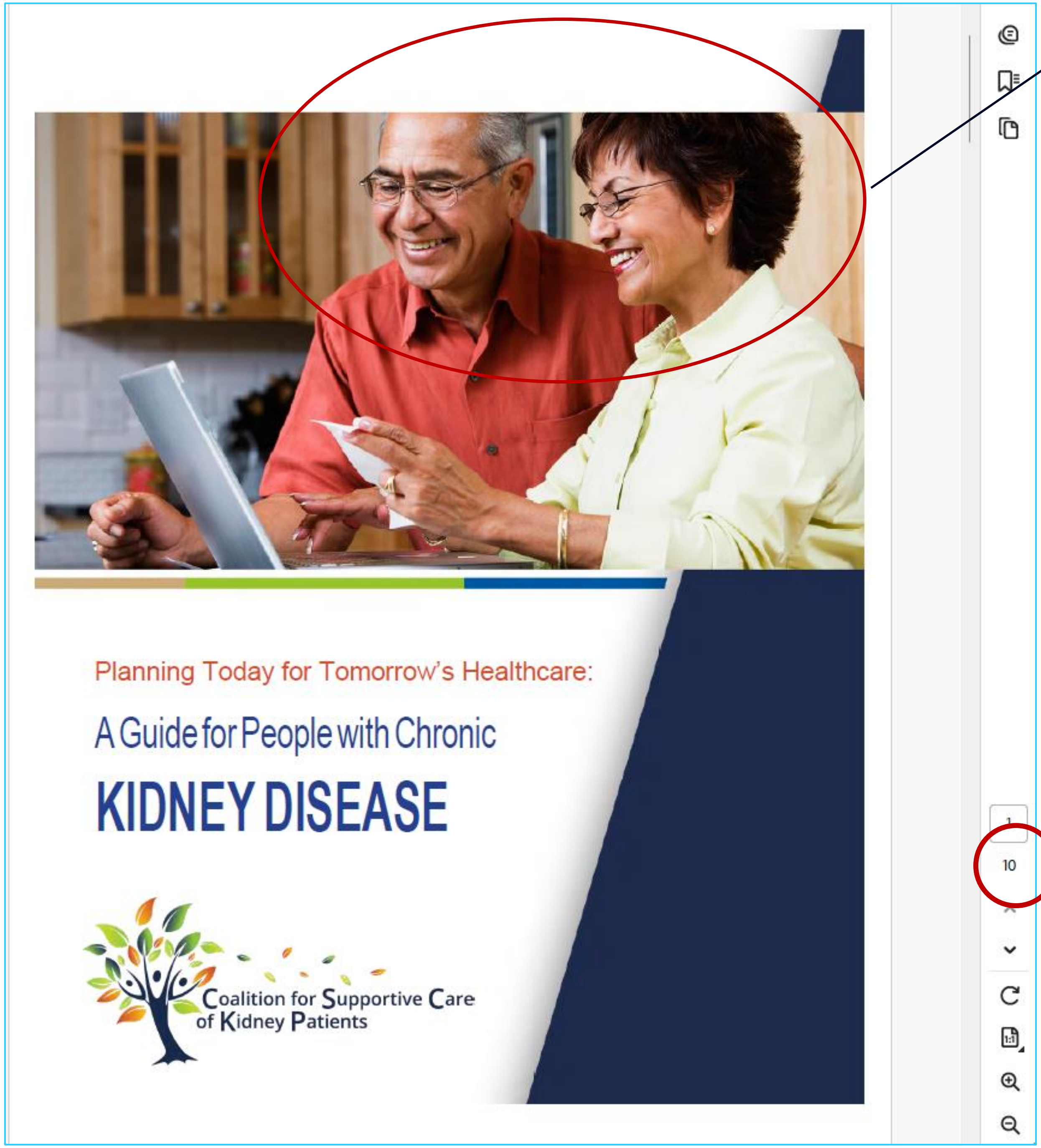


Planning Today for Your Healthcare Tomorrow:

A PERSONAL GUIDE

MY WAY

Make Your Wishes About You



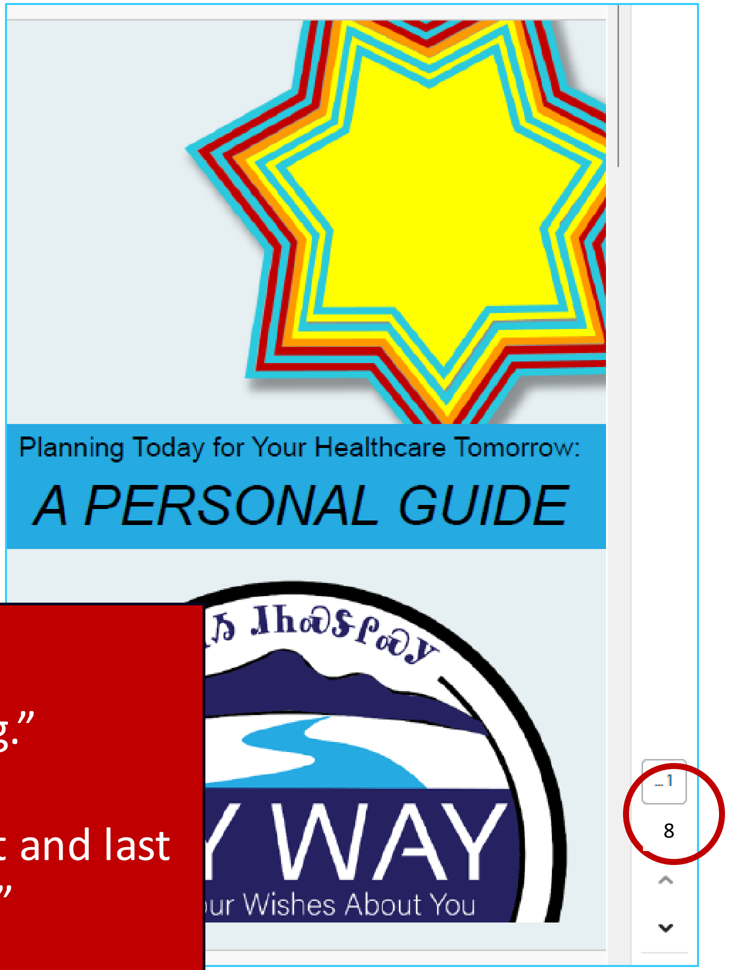
Planning Today for Tomorrow's Healthcare:

A Guide for People with Chronic

KIDNEY DISEASE

Coalition for Supportive Care of Kidney Patients

"Why are they smiling?"

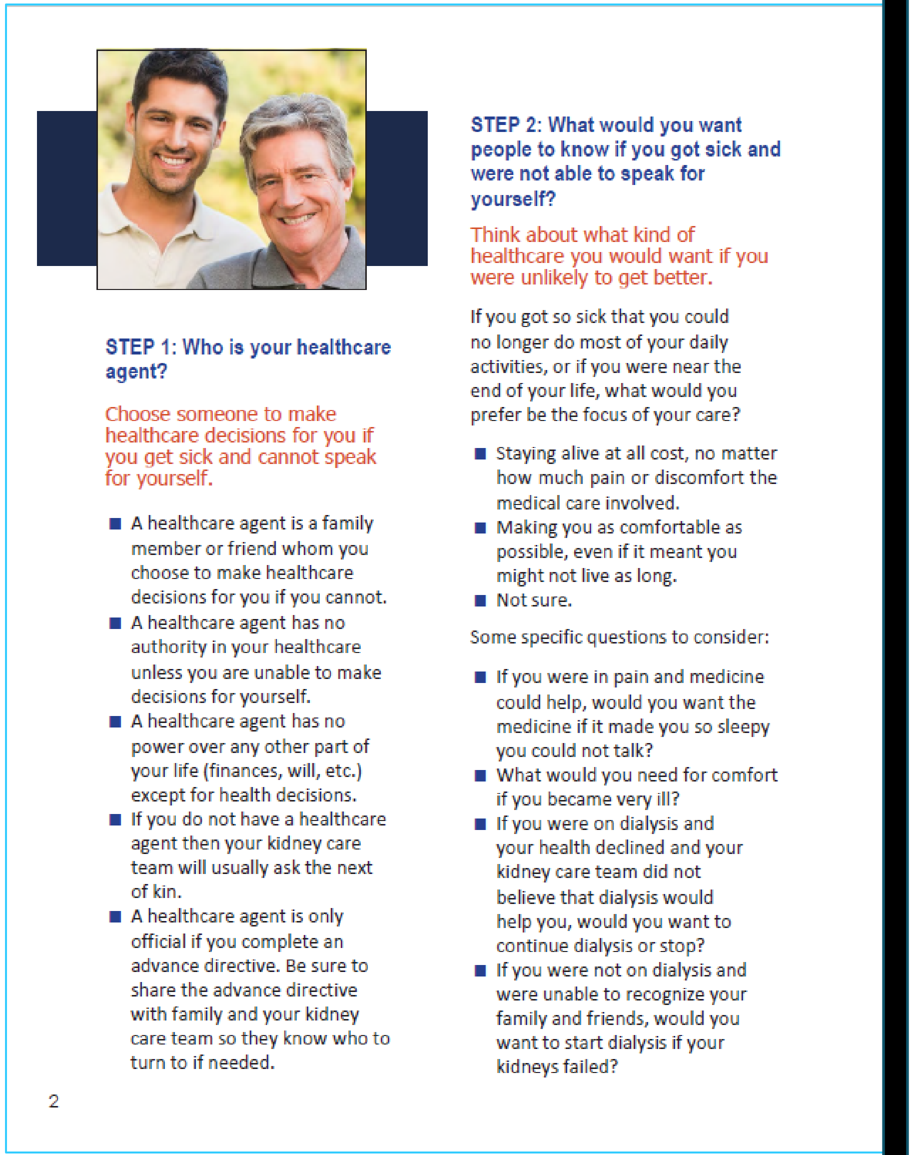


Planning Today for Your Healthcare Tomorrow:

A PERSONAL GUIDE

"It's too long."

"I'd look at the first and last pages only."



STEP 1: Who is your healthcare agent?

Choose someone to make healthcare decisions for you if you get sick and cannot speak for yourself.

- A healthcare agent is a family member or friend whom you choose to make healthcare decisions for you if you cannot.
- A healthcare agent has no authority in your healthcare unless you are unable to make decisions for yourself.
- A healthcare agent has no power over any other part of your life (finances, will, etc.) except for health decisions.
- If you do not have a healthcare agent then your kidney care team will usually ask the next of kin.
- A healthcare agent is only official if you complete an advance directive. Be sure to share the advance directive with family and your kidney care team so they know who to turn to if needed.

STEP 2: What would you want people to know if you got sick and were not able to speak for yourself?

Think about what kind of healthcare you would want if you were unlikely to get better.

If you got so sick that you could no longer do most of your daily activities, or if you were near the end of your life, what would you prefer be the focus of your care?

- Staying alive at all cost, no matter how much pain or discomfort the medical care involved.
- Making you as comfortable as possible, even if it meant you might not live as long.
- Not sure.

Some specific questions to consider:

- If you were in pain and medicine could help, would you want the medicine if it made you so sleepy you could not talk?
- What would you need for comfort if you became very ill?
- If you were on dialysis and your health declined and your kidney care team did not believe that dialysis would help you, would you want to continue dialysis or stop?
- If you were not on dialysis and were unable to recognize your family and friends, would you want to start dialysis if your kidneys failed?

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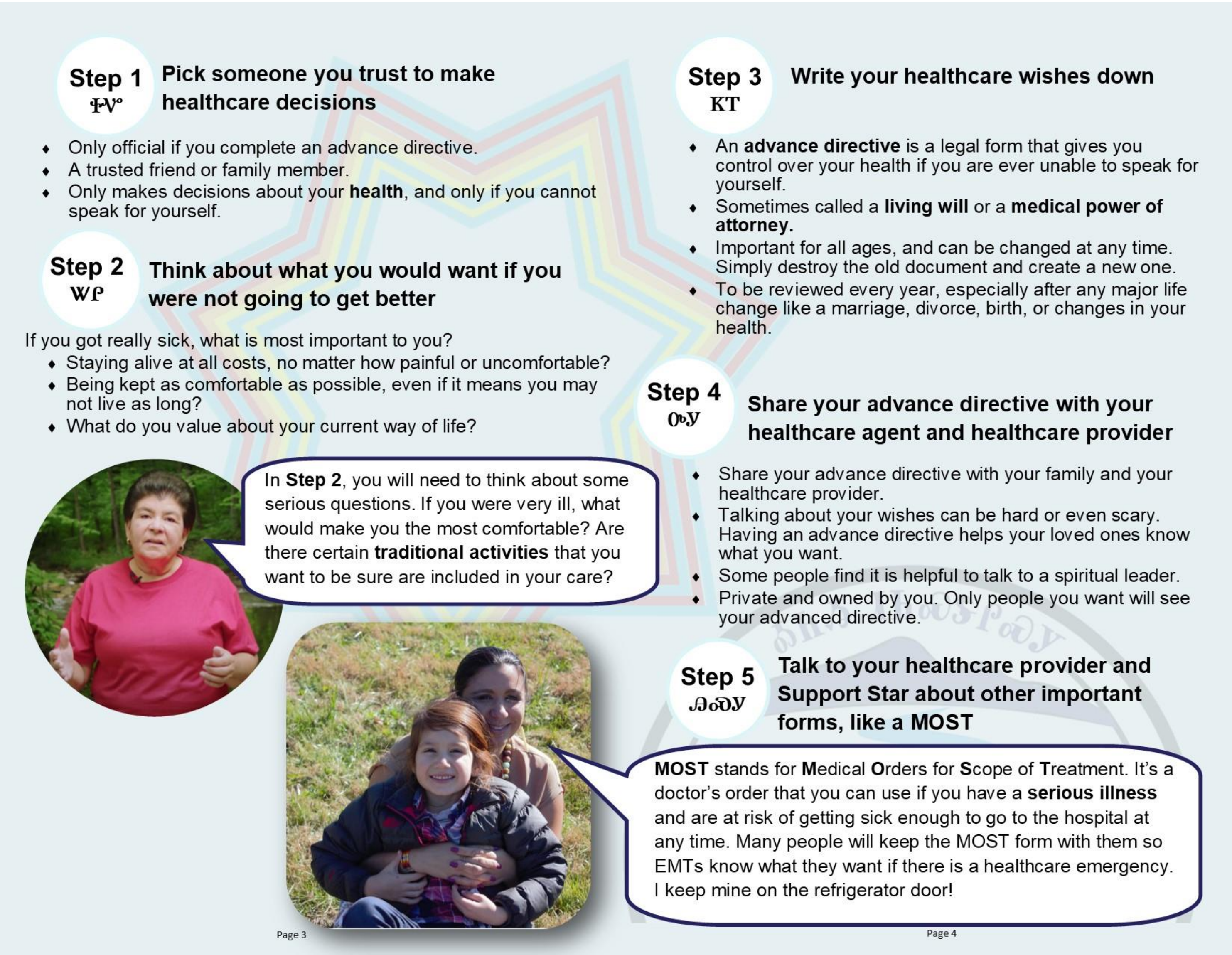


Step 1 ᏌᏊ **Pick someone you trust to make healthcare decisions**

- Only official if you complete an advance directive.
- A trusted friend or family member.
- Only makes decisions about your **health**, and only if you cannot speak for yourself.

Step 2 ᏔᎵ **Think about what you would want if you were not going to get better**

If you got really sick, what is most important to you?
- Staying alive at all costs, no matter how painful or uncomfortable?
- Being kept as comfortable as possible, even if it means you may not live as long?
- What do you value about your current way of life?

In **Step 2**, you will need to think about some serious questions. If you were very ill, what would make you the most comfortable? Are there certain **traditional activities** that you want to be sure are included in your care?

Step 3 ᏦᎢ **Write your healthcare wishes down**

- An **advance directive** is a legal form that gives you control over your health if you are ever unable to speak for yourself.
- Sometimes called a **living will** or a **medical power of attorney.**
- Important for all ages, and can be changed at any time. Simply destroy the old document and create a new one.
- To be reviewed every year, especially after any major life change like a marriage, divorce, birth, or changes in your health.

Step 4 ᏅᎩ **Share your advance directive with your healthcare agent and healthcare provider**

- Share your advance directive with your family and your healthcare provider.
- Talking about your wishes can be hard or even scary. Having an advance directive helps your loved ones know what you want.
- Some people find it is helpful to talk to a spiritual leader.
- Private and owned by you. Only people you want will see your advanced directive.

Step 5 ᎯᏍᎩ **Talk to your healthcare provider and Support Star about other important forms, like a MOST**

MOST stands for **M**edical **O**rders for **S**cope of **T**reatment. It's a doctor's order that you can use if you have a **serious illness** and are at risk of getting sick enough to go to the hospital at any time. Many people will keep the MOST form with them so EMTs know what they want if there is a healthcare emergency. I keep mine on the refrigerator door!

Page 3

Page 4

Original MY WAY:
English only, text heavy, stock images

Culturally Tailored MY WAY:
English and Indigenous language; text is heavily edited; images include tribally significant content, familiar faces, and all ages

MY WAY Patient Video

Support Stars

- Receive intensive training on MY WAY curriculum
- 6-hour training, includes:
  - What is an advance directive
  - Foundations in motivational interviewing
  - Cultural considerations
  - Specific lesson plans for each step of the MY WAY Tool

Support Stars

Curriculum includes:

- Worksheet with action plans for participants
- Follow-up items
- Stepwise repetition of motivational interviewing skills (ask, listen, inform, plan)
- Case studies
- Role-play exercises
- Local resources list

MY WAY Research Overview

Intense community engagement in the cultural tailoring that spanned approximately 2 years before we offered the MY WAY program.

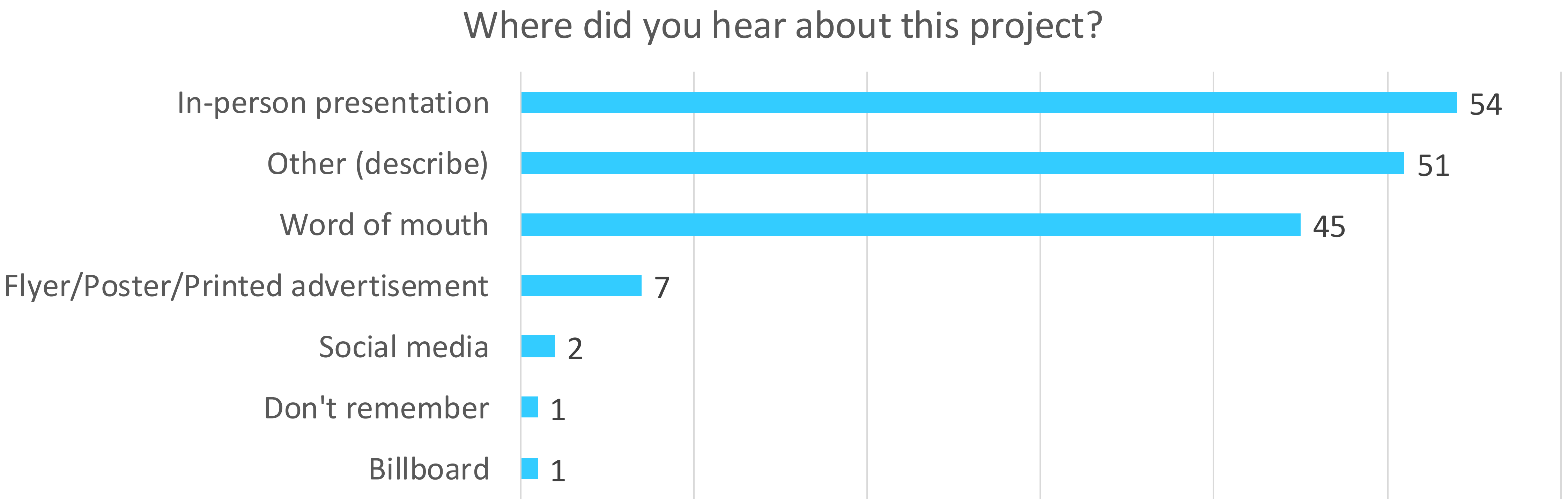
We used a waitlist design and split participants into two groups. Participants completed a baseline survey and then were asked to attend a community information session followed by a private sharing session with a trained Support Star.

Eight weeks after these sessions, a follow-up survey was conducted to see how participants' perceptions, readiness, and self-efficacy to engage in advance care planning might have changed. The survey also provided data regarding the number of participants who completed an advance care plan.

MY WAY is funded by the National Institutes of Health (#R21NR019910).

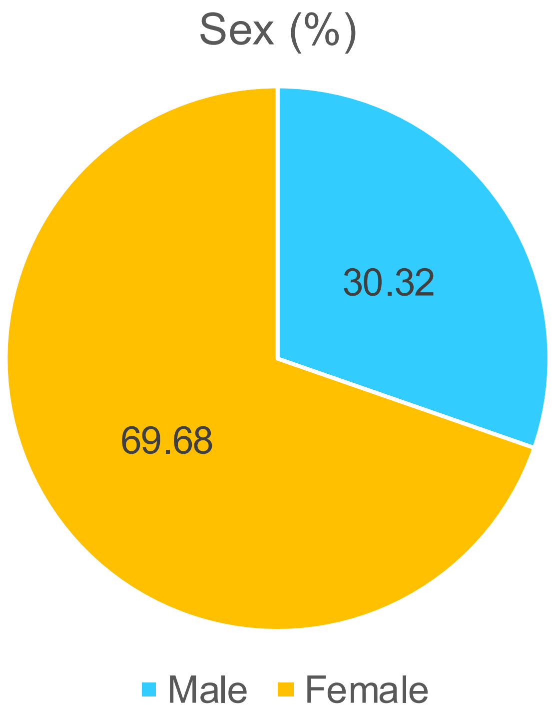
Recruitment

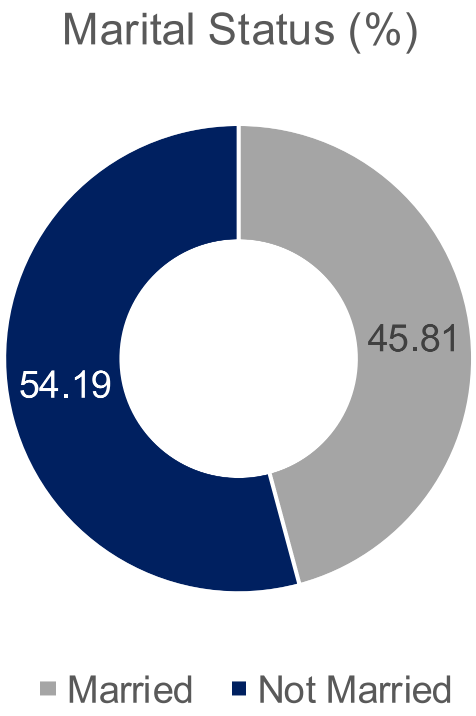
- 166 participants completed an enrollment interview to determine eligibility and interest
- Participants were recruited from a single tribal community
- All were age 18 or older



Participants

- Of those enrolled, 155 participated in at least one aspect of the study.
- Participants were split into a test group (n = 114) and a waitlist group (n = 41); both groups had similar characteristics before program participation.





Participant Demographics

65

Years old on average

80%

Self-health rating of “good” or better

74%

Retention from baseline to follow-up

64

More people with advance care plans

77%

Attendance in all program components

Community Information Sessions

Hosted 14	
	Community clubs (9)
	Senior centers (3)
	Women’s auxiliary (1)
	Extension office (1)

Sharing Sessions

Hosted by trained Support Stars (two were retired nurses and death doulas, one was a tribal member and retired social worker)

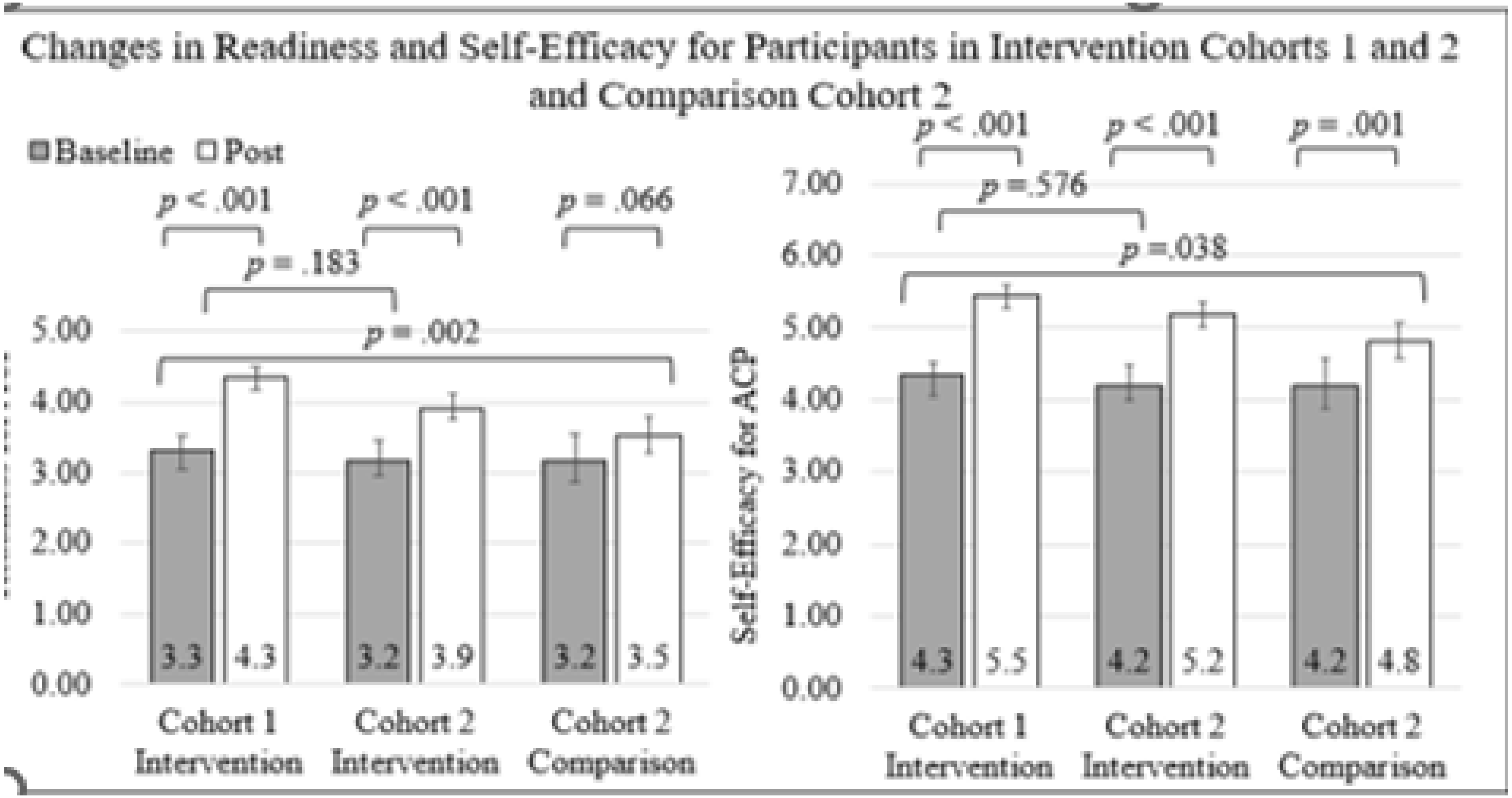
1:1 meetings, encouraged family members to be present, location of their choice

Required to be notarized with two witnesses

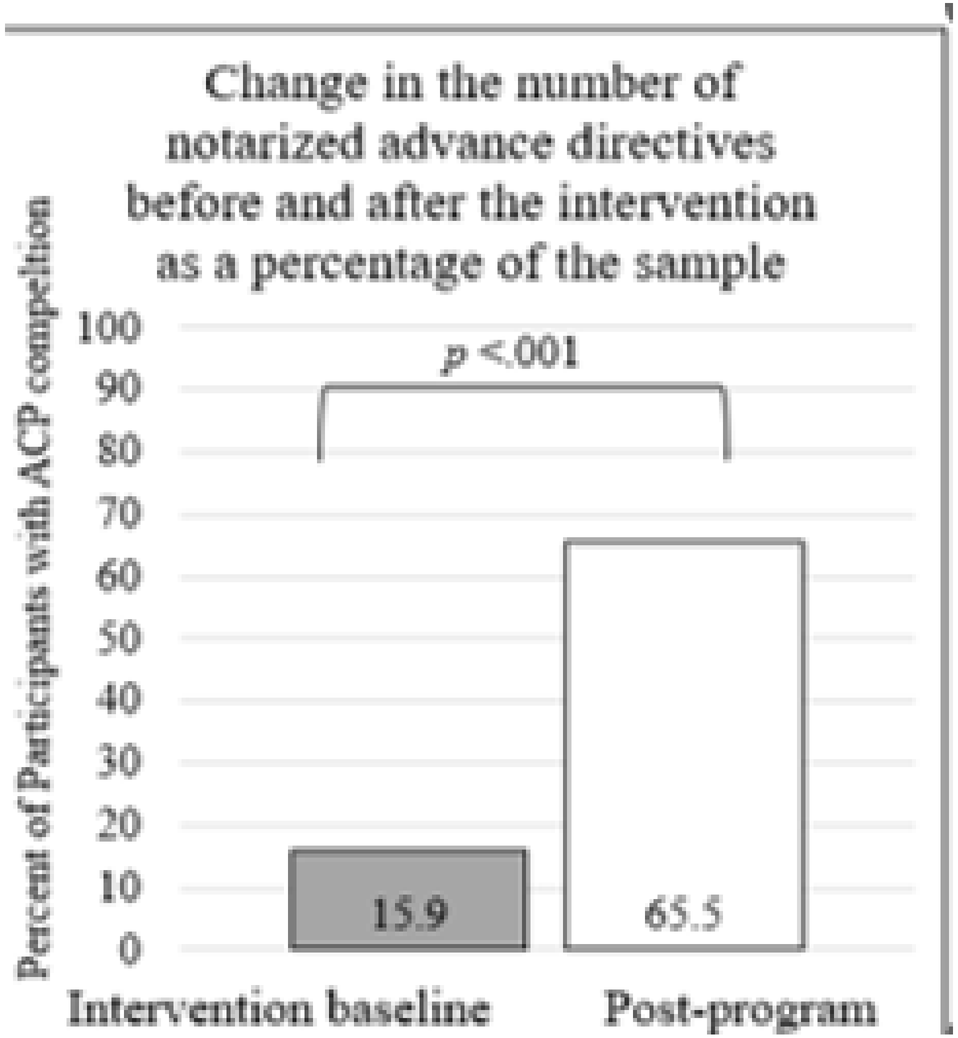
Changes in Barriers and Facilitators

Measure	Pretest	Posttest	Change
BARRIERS			
Average agreement with barrier statements	—	—	↓ 5.2%
Exception: "I do not wish to make decisions about healthcare … I prefer to leave the choices to my doctors"	7.5%	10.2%	↑ 2.7%
FACILITATORS			
Average agreement with facilitator statements	—	—	↑ 6.3%
Exception: "I want to avoid conflict among family members by making my wishes clear"	—	—	Slight ↓
Exception: "I think making decisions about healthcare I would want will make it more likely I will get the care I want"	—	—	Slight ↓

Readiness and Self-Efficacy



Changes in Readiness and Self-Efficacy for Participants in Intervention Cohorts 1 and 2 and Comparison Cohort 2



Advance Directive Completion Rates

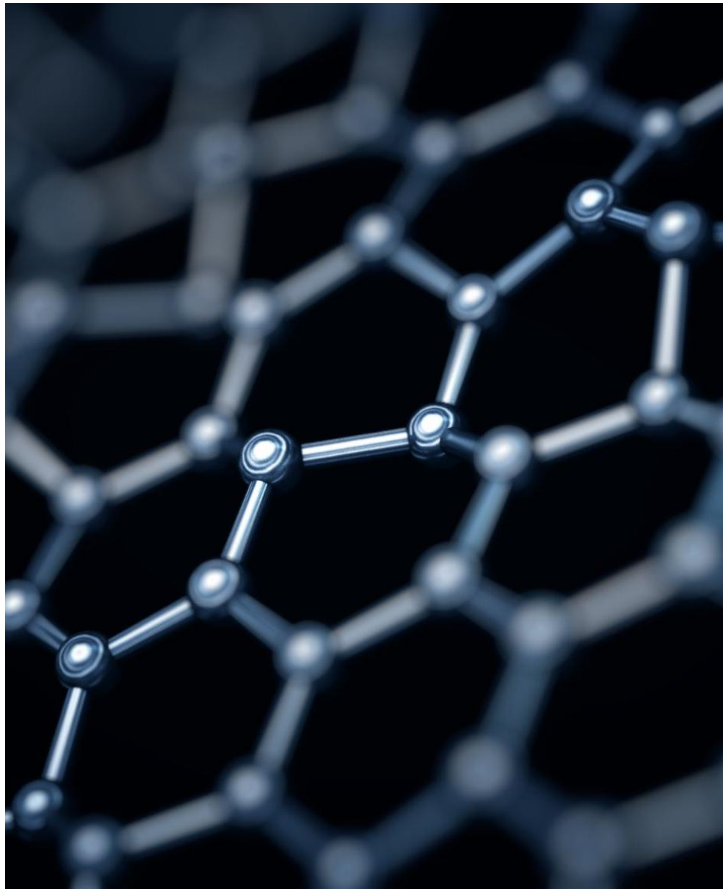
Summary

Culturally tailoring this intervention resulted in positive outcomes

Significant increases in:

- Readiness to approach advance care planning
- Self-efficacy to engage in end-of-life planning
- Completion of an advance care plan

Advance care planning behavioral shift may result in better end-of-life outcomes for people in this community over time.



Resources to Assist with End-of-Life Planning

Resources to Assist with End-of-Life Conversations

The MY WAY brochure lives online at Western Carolina University.

The Support Star training guide also lives online.

Additional Resources

- American Bar Association
- PREPARE (PrepareForYourCare.org)
- National POLST Collaborative (polst.org)
- Mayo Clinic Living Wills and Advance Directives
- AARP

References Cited

1. Kwak, J., Cho, Y. I., Lee, Y. S., Noh, H., & Roh, S. (2019). Differences in advance care planning between American Indian and White older adults. *Research in Gerontological Nursing*, *12*(1), 34–43. https://doi.org/10.3928/19404921-20181212-02
2. Emerson, M. A., Spees, L. P., Jackson, B. E., Fariman, S., Begay, J., Morris, H. N., Salas, A. I., Baggett, C. D., Akinyemiju, T., Bell, R. A., & Wheeler, S. B. (2025). End-of-life care quality for American Indians with cancer. *JNCI: Journal of the National Cancer Institute*, *117(*6), 1188–1197. https://doi.org/10.1093/jnci/djaf007
3. Anderson, E., Goins, R. T., Abdulsalam, R., Jiang, L., & O'Connell, J. (2025). End-of life care disparities experienced by American Indian and Alaska Natives peoples: An analysis of data from the 2019 Medicare Master Beneficiary Summary File. *Journal of Palliative Medicine*, *28*(9), 1185–1192. https://doi.org/10.1089/jpm.2024.0481
4. Goins, R. T., Haozous, E. A., Anderson, E., & Winchester, B. (2024). Cultural tailoring advance care planning for an American Indian community: Make your wishes about you. *Ethnicity & Health, 29*(8), 908–923. https://doi.org/10.1080/13557858.2024.2401830

Thank You

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Questions?