

NHPCO Project ECHO 2023

Equity Where It Matters

**Advancing Equity in Serious Illness and End-of-Life
Care: A Data Analysis**

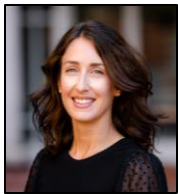
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Disclosures

Disclosure

The planners and faculty disclose that they have no financial relationships with any commercial interest.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. We ask all participants to take the survey as it will help us to improve future sessions.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants - introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today's Agenda

- Overview of hospice and palliative care through Diversity, Equity and Access lens
- Focus on current issues and utilization
- The roadmap to solutions and long-term change
- Case Based Learning: The Power of Communication
- Discussion
- Takeaways
- Close Session

Session Faculty

- Aparna Gupta, DNP, FACHE, CPHQ
- Vice President, Quality
- National Hospice and Palliative Care Organization
- Nicole McCann-Davis, MSC
- Director of Strategic Planning
- Eversana Intouch



The facts – what one study revealed

Study commissioned by National Hospice and Palliative Care Organization in 2021-2022

- ❑ Communities studied : Black, Hispanic and LGBTQ+
- ❑ Nationwide survey of adults (n=1200) 21 years and above, who have been involved in hospice related experiences
- ❑ Results suggest : ***What Matters Most?***
 - ❖ **Location:** Respondents are unaware that hospice care can be delivered at home
 - ❖ **Information:** Variability in “most trusted source” of information, what is the “right time”?
 - ❖ **Finances:** Navigating healthcare is confusing, unaware of the Medicare Hospice Benefit
 - ❖ **Experience:** A religious/ spiritual component is vital; culture, language and sexual orientation are potential barriers

<https://www.nhpco.org/education/tools-and-resources/diversity/>

Upstream focus - diversity in palliative care

- ❑ Racism and lack of equity in palliative care is a public health crisis
- ❑ Sources of inequity are reflective of those influencing access to specialist palliative care and include
 - diagnosis (cancer vs non-cancer)
 - socio-economic status, gender identity
 - racial and ethnic identity
 - employment status
 - language
- ❑ Determinants of end-of-life care is central to a public health approach to palliative care
- ❑ There is a need to focus on standardize reporting of race and ethnicity, strive for diversity, equity, and inclusion, and prioritize the study of racial and ethnic disparities in hospice and palliative care research

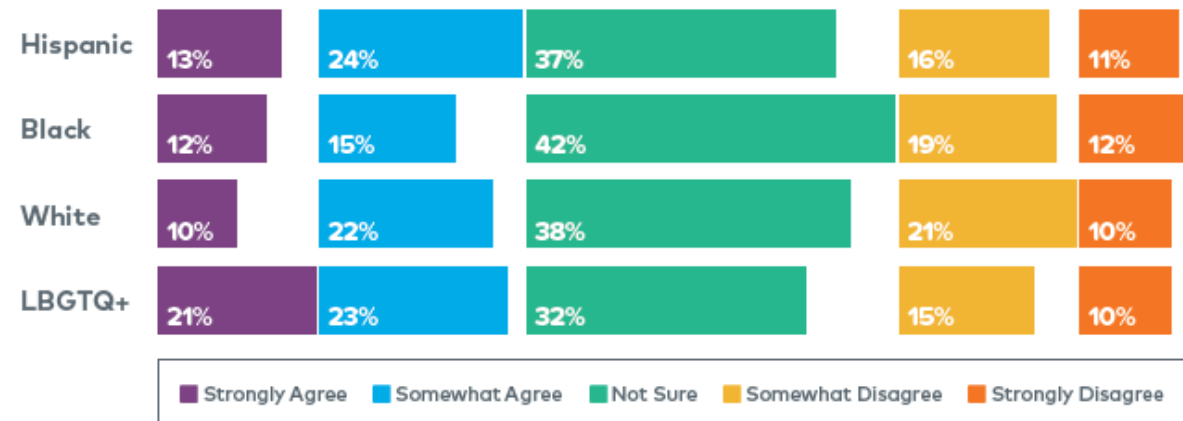
Rhodes, R. L., Barrett, N. J., Ejem, D. B., Sloan, D. H., Bullock, K., Bethea, K., ... & Johnson, K. S. (2022). A review of race and ethnicity in hospice and palliative medicine research: representation matters. *Journal of Pain and Symptom Management*.

Bringing It All Together

Doctors often wait too long to talk about hospice, making it a crisis decision to use it.

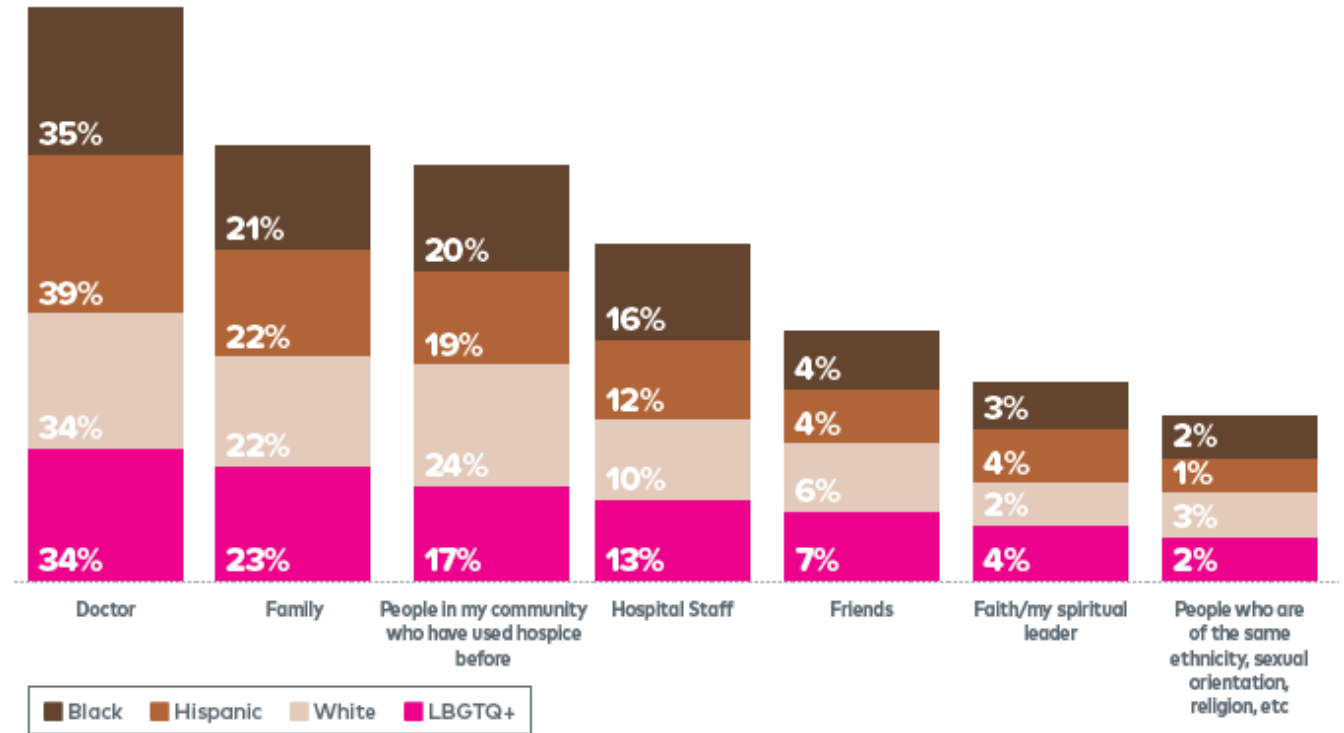
Community partnerships continue to be very important, however, patients and loved ones trust their doctors more than anyone else to refer them to a specific hospice.

Almost ½ of LGBTQ respondents believe doctors wait too long to talk about hospice, making it a crisis decision. A significant number of Hispanic respondents feel the same.



Bringing It All Together:

Who would you trust to recommend a specific hospice to you?



<https://www.nhpco.org/education/tools-and-resources/diversity/>

Bringing It All Together:

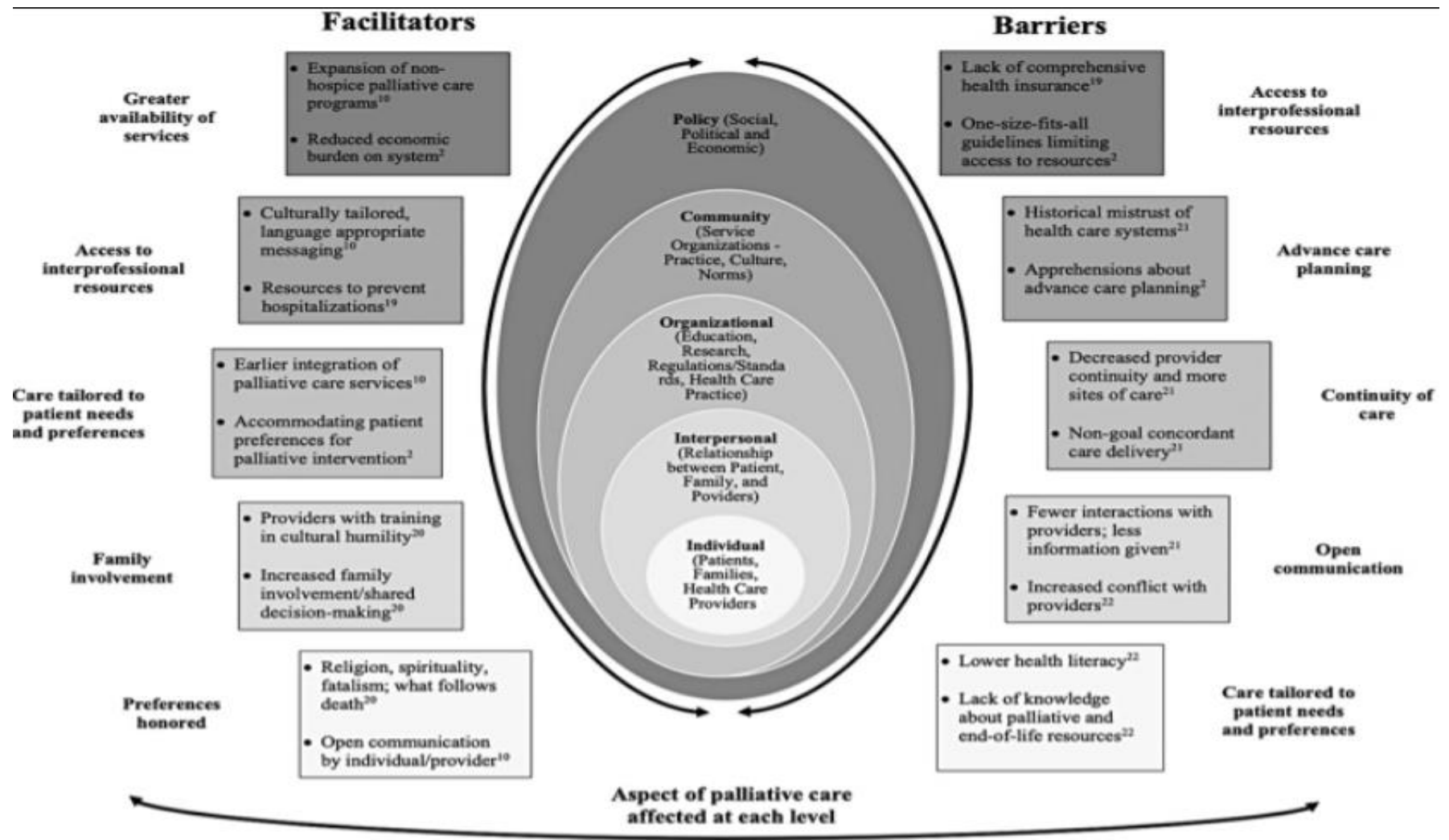
Hospice and Language

Language can be a significant barrier for non-native English Speakers. More than half (**52%**) of **Hispanic respondents** said they would need hospice workers who spoke their loved one's language in order to feel comfortable.

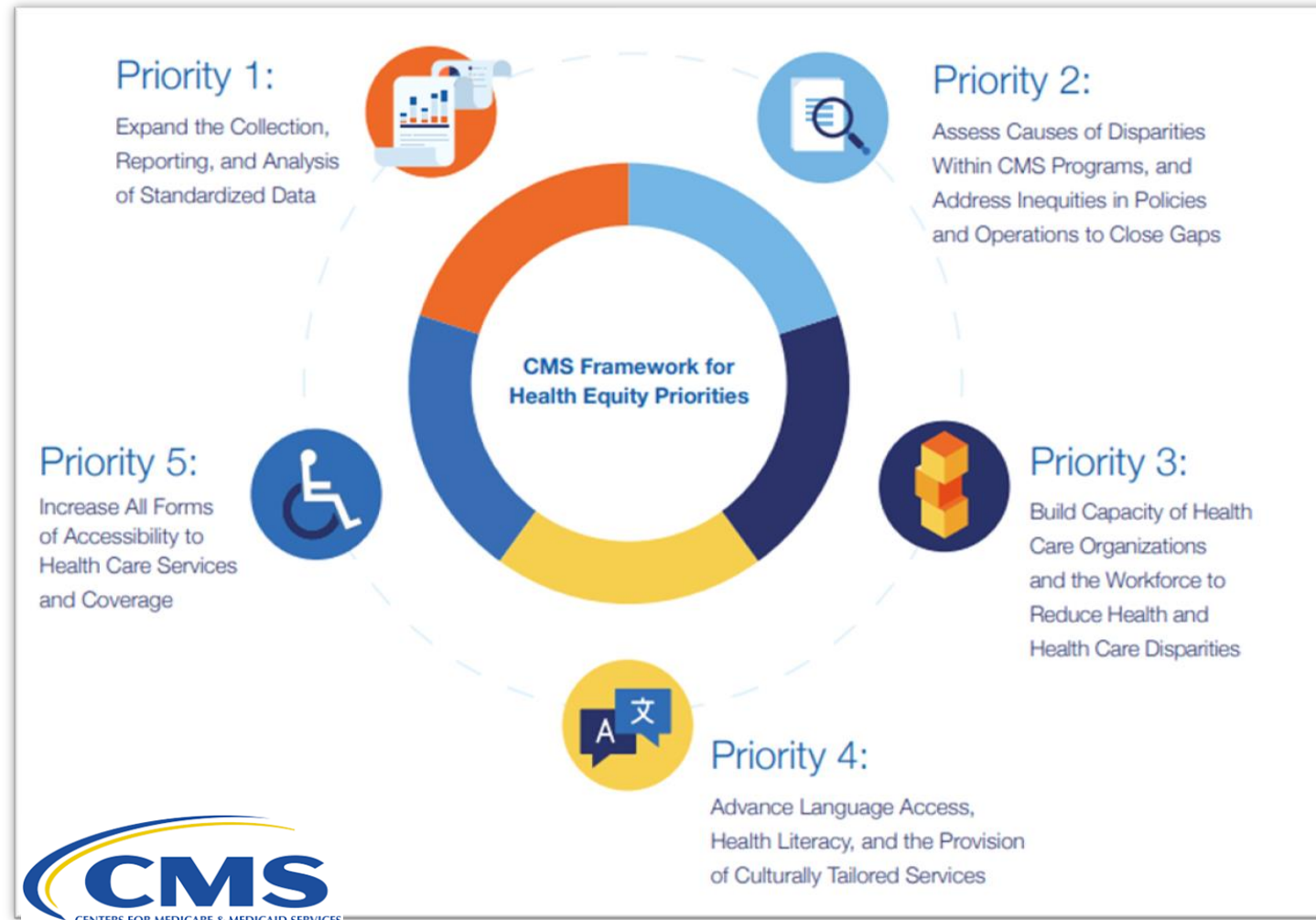


<https://www.nhpco.org/education/tools-and-resources/diversity/>

Bringing It All Together



Bringing It All Together



<https://www.cms.gov/files/document/cms-framework-health-equity-2022.pdf>

The Power of Communication

Situation

Mrs. Garcia is a 62-year-old woman with a hx of hypertension, hypothyroidism and advanced dementia consistent with Alzheimer's type dementia. She experienced a gradual functional decline and lost her ability to ambulate (FAST 7c) over the past 3 months and is non-verbal and dependent for all ADLs with fecal and urinary incontinence. She was hospitalized 2 weeks ago for an aspiration pneumonia but has improved and currently resides at home consuming approximately 25% of her meals. She has experienced increasing diarrhea, intermittent vomiting, and worsening anorexia related to her dementia over the past 6 weeks.

Mrs. Garcia's PCP recently referred her to a hospice organization for symptom management and they were able to provide a Spanish-speaking hospice consultant to admit her onto service.

Background

- Reside in a suburb of San Antonio, Texas
- Family is very involved with Saint Cecilia Catholic Church.
- Mr. and Mrs. Garcia immigrated to the United States 10 years ago from Mexico and have 3 adult children, 1 of whom lives with them along with her family (2 grandchildren).
- Family history of dementia, mother died of dementia later in life
- The primary language spoken in the home is Spanish though Mr. and Mrs. Garcia can read some English. Mrs. Garcia's understanding of the English language has diminished along with her memory.
- Mrs. Garcia is a caring mother and grandmother who is known in the neighborhood for her cooking, open heart, and warm smile. She is a proud Latina woman!
- Mr. Garcia believes that hospice care is temporary as God is in control and will make his wife better.
- The family's top concern is addressing the anorexia and they've prioritized keeping her well-fed with her favorite foods.
- The Garcia children are concerned about their 65-year-old father's ability to be the primary caregiver for their mother.

Hospice Team

Hospice Care Consultant	Admitting Nurse	Chaplain	Social Work
<ul style="list-style-type: none">• Hispanic/cis-gender male• Bilingual English/Spanish speaker• Resides in a community similar to the Garcia's that is 20 minutes away.	<ul style="list-style-type: none">• White/cis-gender female• English speaker• Resides 30 minutes from the Garcia's.	<ul style="list-style-type: none">• White/cis-gender male• English speaker• Resides 25 minutes from the Garcia's.	<ul style="list-style-type: none">• White/cis-gender female• English speaker• Resides 3 miles away from the pt.

Assessments

Completed by the Social Worker within the first 3 days of admission

- SDOH
 - Questions were asked and the family appeared puzzled while answering. Based on the responses, there was no cause of concern.
- Spiritual
 - The Garcia family are faithful members of the Catholic religion.

Completed by the Chaplain with assistance from the Hospice Care Consultant within the first 5 days of admission

- Spiritual
 - Learned that Mr. & Mrs. Garcia are very involved in their local church.
 - Hospice team joined the family in prayer.

Completed by the Admissions Nurse within 24 hours of admission

- Full head to toe
- Bereavement
 - Family wasn't interested in considering bereavement support at this time.

Assessments Pros/Cons

Positive

- The Hospice Care Consultant speaks Spanish.
- The Social Worker lives in a neighboring community (familiar with it but also stereotypes based on their experiences).
- Chaplain asked the hospice consultant to attend their first visit to help put the family feel comfortable.
- The Chaplain and Hospice Care Consultant participated in the family prayer.

Challenges

- There is no connection between the hospice team and the pts religious community.
- There was no explanation of why the SDOH questions were being asked.
- Assessment questions were directed towards completed the more English-speaking members of the family rather than the patient/spouse.
- The Admissions Nurse engaged the pts grandchild to interpret.
- The Chaplain came during the day while the adult children were still working. The only family in attendance were Mr. Garcia and the two grandchildren.

Recommendations / Conclusions

- Written materials should be available in a variety of languages.
- Even if a patient and/or their loved ones can read English, offer other language options during every admission to demonstrate a commitment to honoring your diverse patient population.
- Be transparent regarding language expectations of your team with your patients and/or their loved ones.
- Be intentional with hiring employees who are bilingual if it will improve the quality of care experienced by your patients and/or their loved ones.
- Develop best practices for engaging with interpreters to ensure all communication maintain the qualities of care and compassion.
- But wait, there's more!

”

*As long as they speak
Spanish, that's basically my
only requirement. If they're
human, and they speak
Spanish, I'm good with that.*

What more can be done to support the Garcia family?

Outcome

10 days into Mrs. Garcia's hospice service, the family decided to revoke hospice care.



27 days later, Mrs. Garcia was readmitted to the hospital and members of her congregation came to visit. After praying with the family, one member shared with the family the positive hospice care experience received by her mother.



2 days later, Mrs. Garcia was readmitted onto hospice service at home.



55 days later, Mrs. Garcia died peacefully at home surrounded by her family.

Upcoming Project ECHO Sessions

Date: January 19, 2023

Topic: Check Ourselves Before We Wreck Ourselves: Recognizing and reducing provider bias

Date: February 2, 2023

Topic: Caring Through Crisis

Registration Link:

<https://nhpco.zoom.us/meeting/register/tZEsfu-trz4oGtQeKfw41UEIYNwjSli8QCBF>

Session Evaluation: [Project ECHO Session Evaluation](#)

Access NHPCO Project ECHO webpage at:

<https://www.nhpco.org/projectecho/>