



Elea Institute



Caregiver Research & Next Steps
with Emergence Creative



NPHI National Partnership
for Healthcare and
Hospice Innovation

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A close-up portrait of an elderly Black man with a white goatee, wearing a dark fedora and a blue and white striped shirt. He is looking slightly to the right of the camera with a gentle expression. The background is a blurred outdoor setting with green foliage and a brick wall.

01

Introduction

NPHI + Emergence: Summary of Work To Date

DESK RESEARCH

Competitive landscape, case studies, academic literature, news coverage

QUANTITATIVE SURVEY

Views and Experiences of Aging & End-of-Life Care in the US

BRAND POSITIONING

New strategic positioning concept and language for NPHI

QUALITATIVE RESEARCH

Caregiver Experiences and Perceptions of Declining Health

NPHI SUMMIT 2023

Keynote, breakout working sessions, member engagement

SUBJECT MATTER EXPERT INTERVIEWS

1:1 discussions with 30+ leaders in the field

WORKSHOPS

Multiple strategy sessions with NPHI leadership and select NPHI members

VISUAL IDENTITY

Development of refreshed brand assets for NPHI materials

FIELD-BUILDING BLUEPRINT

People Over Profits: A Values-Based Movement for Declining Health

MEMBER MATERIALS

Messaging toolkit, photography library, strategic recommendations



02

Caregiver Experiences and Perceptions of Declining Health

Research Methodology

Format:

- 6 virtual **1:1** interviews (1.5 hours each)
- 6 virtual group Interviews with **3 participants** per group (2 hours each)

Participants:

Diverse set of **31 caregivers** recruited from around the country

- Approximately census-balanced mix of race and ethnicity
- Gender skewed female, reflecting national trends in caregiver status
- Representation of a range of health issues (dementias, cancers, and heart failure were most common)
- Mix of relationships to patient, including spouses, children, parents, and other relatives
- 1 caregiver of a pediatric patient (recruiting for this category posed serious challenges – a key learning for future research)

Content/Discussion:

- Moderators followed a discussion guide with detailed questions around key facets of the caregiver experience and their “journey” through the healthcare system
- Key themes included: practical considerations, interactions with healthcare system, social and interpersonal dynamics, religion and spirituality, financial challenges, caregiver health and wellbeing, and more
- Participants were asked to imagine the ideal healthcare experience for themselves and their loved one, with moderators probing on key terminology (e.g. “comfort,” “advanced illness,” “palliative,” “hospice,” etc.)

When Defining Care...



The terminology is confusing.

Caregivers' lack of familiarity with certain terms leads to confusion. The term "comfort care" resonates across the board as it addresses the reality of the situation in plain, human language.



The options are perplexing.

Navigating the healthcare system and being aware of the various types of care available is challenging. These unknown unknowns hinder accessibility to services and are a source of stress and insecurity.



Wishful thinking sets the expectations.

Care is often understood from a personal perspective rather than a service perspective, encompassing a wide range of activities such as cooking, cleaning, laundry, driving, and meal delivery.



There's no place like home.

Home care services are generally preferred over permanent residential care facilities, as there is often skepticism and hesitation towards the latter.

COMFORT CARE

This term emotionally resonates with people and conveys the philosophy of making the journey as smooth as possible.

PALLIATIVE CARE

People are unfamiliar with the term and generally unclear about how it differs from hospice care.

HOSPICE CARE

The term is widely and favorably understood, but most participants view it as an option for the final days of life. Looking back on the experience, many wish they had started sooner.

SYMPTOM MANAGEMENT CARE

People are unfamiliar with the term. It has a detached and inhuman connotation that doesn't resonate.

SERIOUS/ADVANCED ILLNESS CARE

The term is also largely unknown and overly technical. It can come across as cold or clinical.

Two Sides of Caregiving

The Weight

Forced into an imposed destiny

The responsibility of caring for elderly or ill family members is often thrust upon daughters, wives, and granddaughters regardless of their willingness.



Trapped in the red tape

The weight of bureaucracy is burdensome, with financial pressures, administrative chaos, and a sea of obligations creating an overwhelming situation.



Drowning in emotions

Emotional turbulence is a caregiver's companion, with waves of acceptance and denial, hope and despair, and constant doubt and hypervigilance.



Isolated in a lonely journey

Caregiving can be a lonely journey, with individuals unexpectedly thrown into unfamiliar roles, experiencing social isolation and a lack of recognition.



Neglecting their own health

Exhaustion, stress, depression, and weight fluctuations are common when one overlooks their own health needs while striving to be a pillar of support for their loved ones.



The Beauty

Rise to the occasion

Caregiving demands skills they never knew they had. Dedicated caregivers rise to the occasion with education, resilience, and unwavering commitment, giving them a sense of accomplishment.



Find comfort in faith

Caregivers may regain a sense of purpose and meaning when confronting the imminent death of a loved one. Drawing closer to the divine can provide strength and understanding in a challenging time.



Honor the sacrifice and privilege

Cherishing the time left with their loved one is a gift that they wouldn't trade. By providing respect and dignity, caregivers allow their loved ones to close their last chapter with grace.



Heal together

Discovering a purposeful role within the family can foster a stronger sense of unity and help mend past grievances.



Gain perspective

Facing the reality of illness and death fosters a new perspective on the fleeting nature of life and heightens one's awareness of the value and beauty of what they have.



Human Framework: Caregiver Archetypes

PROACTIVE PROBLEM-SOLVERS

EMOTIONAL EXPERIENCE:

DETERMINATION. Ready to face and tackle the challenges ahead with energy and perseverance, their experience is the most positive, driven by a feeling of usefulness and even pride.

APPROACH TO CARE:

OWNERSHIP. Their commitment is more "chosen" and they view caregiving as a problem to be solved. They want to take destiny into their hands, so they are proactive, well-informed, and open to seeking external support.

TENSIONS:

HOPE VS DESPAIR. How to support my loved one in the final journey without giving up hope?

EFFECTIVE COORDINATORS

EMOTIONAL EXPERIENCE:

PRAGMATISM. They have a rational attitude towards the situation and want to feel in control. They are in close supervision of their loved one. They strongly believe in their ability to positively impact the condition of their loved one through top-notch treatments and services.

APPROACH TO CARE:

CONTROL. They have found a way to manage the situation despite the sometimes severe loss of autonomy of their loved one – thanks to solid relational, emotional and financial resources, and the more frequent use of professional help.

TENSIONS:

CHOICE VS INFORMATION. How do I determine the right course of action when I lack sufficient guidance and information?

BALANCED EMBRACERS

EMOTIONAL EXPERIENCE:

ACCEPTANCE. They take their situation with more perspective, accepting that the end of life is a natural part of it. Out of love, respect, and tradition, they try to live in the most harmonious possible way and put their loved one's needs first.

APPROACH TO CARE:

HONOR. They take their role as an honor to give back what their loved ones had given to them. Knowing their time is finite, they want to enjoy the time left to the fullest with no regrets. Being part of a tight community is a great source of emotional and organizational support.

TENSIONS:

ENJOYMENT VS DUTY. How to honor and enjoy the time left together when there are so many interferences?

DEVOTED GIVERS

EMOTIONAL EXPERIENCE:

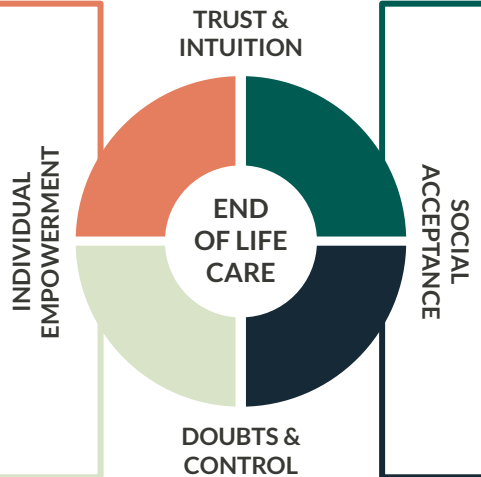
DEVOTION. They commit themselves almost full-time to the care of their loved one. Often desperate and overwhelmed by the situation, they have a very difficult time coping with their situation, suffering from a feeling of powerlessness and a heavy mental burden that can be aggravated by the lack of financial resources.

APPROACH TO CARE:

SACRIFICE. Giving, they are willing to put themselves at the service of their loved one. They tend to delay seeking external support.

TENSIONS:

CONFIDENCE VS POWERLESSNESS. How to feel confident I am doing the right thing when nothing seem to improve the situation?



Proactive Problem-Solvers

EMOTIONAL EXPERIENCE:

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Health Status Skew



Moderate health issues

Those with moderate or early-stage health issues **require less supervision** and experience a gradual decline.

Relationship Status Skew



Siblings or grandchildren

They are **emotionally resilient** and function successfully while providing long-term care for their loved ones.

Ethnicity Status Skew



White

They predominantly come from a cultural background that values **individualism and a hard working mindset.**



Mini Story: Rebecca

Rebecca describes herself as a **lifetime caregiver**, having taken care of her parents, grandparents, and recently her autistic brother. She knows the healthcare system inside out. She shared how necessary it is to surround oneself with the right people and **the right networks and services** in order to be able to hold on for the long haul.



Mini Story: Michelle

Michelle takes care of her grandfather, recently diagnosed with dementia. There is **no time to stop and think** as there are so many things to plan and do. She knows she also needs to **take care of herself** and her own family in order to stay mentally and physically healthy and to **keep going**. Every day is a new challenge but she is ready to take it one day at a time.

Balanced Embracers

Health Status Skew



All health conditions

This factor is of **limited relevance**, as other skews are more influential.

Relationship Status Skew



Children and grandchildren

Kin caring for their elders, **embracing the circle of life**, and giving back to the community.

Ethnicity Status Skew



African-American + Asian-American

Predominantly comprising BIPOC individuals with a **closely-knit and supportive community**.

EMOTIONAL EXPERIENCE:

ACCEPTANCE. They take their situation with more perspective, accepting that the end of life is a natural part of it. Out of love, respect, and tradition, they try to live in the most harmonious possible way and put their loved one's needs first.

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Mini Story: Stacy

Stacy lovingly cared for her late grandmother until she passed away. She took **extended time off work to provide care**, and the hospice team offered gentle support, including organizing a mass for her grandmother. She **treasured the moments** spent talking with her grandmother, learning about her rural upbringing, and her kind-heartedness towards strangers.



Mini Story: Mandip

Mandip, born in India and raised in the US, finds **great reward and honor in caring for her loved ones**, including her parents, in-laws, cousins, and her community. Being part of a **close-knit Indian community** brings immense support, with others readily stepping in to help if she is unable to make an appointment or pick up a prescription.

Devoted Givers

Health Status Skew



Rapidly declining health conditions
Associated with the imminent reality of death, grappling with **fear, grief, and regrets** related to mortality.

Relationship Status Skew



Spouses and children
Typically observed among spouses and children, characterized by a profound **emotional bond** and close connection.

Ethnicity Status Skew



White + African-American
They have **limited financial resources**, which constrain the available options.

EMOTIONAL EXPERIENCE:

DEVOTION. They commit themselves almost full-time to the care of their loved one. Often desperate and overwhelmed by the situation, they have a very difficult time coping with their situation, suffering from a feeling of powerlessness and a heavy mental burden that can be aggravated by the lack of financial resources.

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Mini Story: Diamond

As a young woman balancing school, work, and motherhood, Diamond faces the challenging role of caring for her mother in the final stages of cancer. Despite **emotional ups and downs**, frustration over not being able to fulfill her mother's wish to stay out of the hospital, and **concerns about the quality of care**, Diamond finds strength in her son's unwavering joy.



Mini Story: Cynthia

Cynthia is **devoted** to caring for her 96 year-old mother in the hospital, but struggles to find healthcare workers who treat her mother with the **respect and dignity** she deserves. The **transactional and inhumane care** has taken an **emotional toll** on Cynthia, leaving her frayed and constantly emotional with tissues in hand.

Effective Coordinators

Health Status Skew



Gradual health decline

With a gradual decline, there is more **time to prepare** and anticipate the challenges ahead.

Relationship Status Skew



Children

High emotional toll, but but these **high-functioning individuals** are adept at managing multiple responsibilities.

Ethnicity Status Skew



White

Mostly individuals from **affluent economic backgrounds**, they have the luxury of choice and less financial stress.

EMOTIONAL EXPERIENCE:

PRAGMATISM. They have a rational attitude towards the situation and want to feel in control. They are in close supervision of their loved one. They strongly believe in their ability to positively impact the condition of their loved one through top-notch treatments and services.

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TENSIONS:

CHOICE VS INFORMATION. How do I determine the right course of action when I lack sufficient guidance and information?



Mini Story: Ella

Ella, a mother of two and full-time director of partnerships, faces the challenge of caring for her mother with early dementia in Florida from New York. Despite disagreements and difficulties within the family, Ella takes on the responsibility as the **family organizer**, handling tough situations with a **level-headed approach**.



Mini Story: Alicia

Alicia, a business owner, cares for her mother in the advanced stages of cancer. Adjusting her work schedule to meet her mother's needs, Alicia dedicates herself to ensuring her mother's happiness and comfort. From purchasing sweatsuits to driving her to medical appointments, Alicia is present and involved in her mother's care, **overseeing and ensuring everything goes according to her plan**.

Pediatric Interview: Delilah

Delilah is a writer and event planner from Mississippi, who lost her daughter after a difficult series of health issues that began when her daughter was a child. Just as her daughter was nearing the end of her life, Delilah's husband was diagnosed with Parkinson's, so her caregiver journey continues.

*"Why her? What did she do?
... You can't plan these things.
There's no rhythm, no rhyme,
no method... Sometimes our
responsibilities choose us."*

Ethnicity Cheat Sheet



WHITE

More Isolated, so Toll is Immense

Experiencing significant loneliness, emotional burden, and sadness while providing care.

Try to Do it All by Themselves

Attempting to handle everything alone until reaching a breaking point.

Willingness to Delegate

Considering external care services as an option, provided they find the right one.



AFRICAN AMERICAN

Guided by God

A high level of religiosity brings comfort and guidance during this chapter.

It Takes a Village

The community provides valuable emotional and organizational support.

Hesitant to Seek External Support

Due to a historically-rooted distrust in the healthcare system and a racial gap in healthcare access.



ASIAN AMERICAN

Acceptance of Life's End

Normalizing and accepting the end-of-life phase with a philosophical approach.

Respect for Elders

Feeling a sense of purpose by taking on the role of caring for elderly loved ones.

Multi-generational Household

Feeling a duty to repay the care received in childhood by keeping elderly care in-home.

Decision-Making Journey



STEP 1

DEALING WITH DENIAL

Care recipients often resist external care due to denial, fear, and loss of independence.

"I would gladly accept external help, but my mum doesn't want anyone else in the house or driving her to her treatment."

BREAKING POINT

Caregivers try to honor their loved one's wishes until they reach a breaking point.

"It takes so much of my day to make sure she's ok and tending to her needs. I'm losing more and more of myself, my time, my energy."



STEP 3

STRUGGLE OF THE SEARCH

Limited information on care services and insurance hinders the process of exploring options.

"There's no course that you can take anywhere. You just have to have conversations with people and pieces of information fall from the sky."

INSURANCE LIMITS YOUR OPTIONS

Insurance coverage can limit available options and strongly influences decisions.

"The company we went for was on a list given by my hospital and they had a social worker reach out to figure out insurance coverage."



STEP 5

CRISIS DECIDES FOR YOU

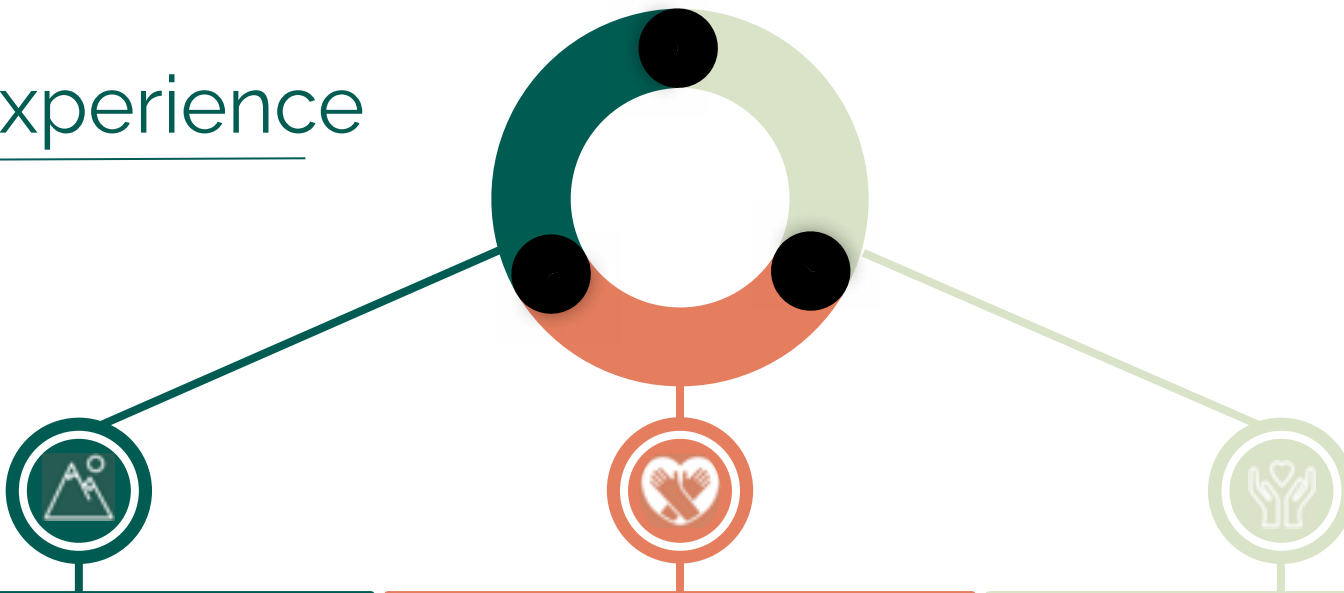
In critical moments, families rely on a doctor's recommendation or familiar organizations.

"She had been in hospital and to rehab. When it looked like it was nearing the end, our doctor's office gave us the name of the hospice company."

STEP 4



The Experience



LOGISTICS MOUNTAIN

Current Situation

- **Steep mountain to climb.** People are too often dealing with logistics on their own, leading to feeling lost, confused, and disempowered.

Unmet Need

- **Lack of clarity.** People need guidance to navigate the complexity of the path ahead.

Ideal

- **Reassurance and empowerment.** Adequate resources and straightforward guidance from professionals would be highly valued.

CARE FOR CAREGIVERS

Current Situation

- **Entirely absent.** Nothing is done for them – yet they need to be heard, seen, and considered.

Unmet Need

- **Lack of recognition.** Absence of acknowledgement and care for their crucial role.

Ideal

- **Attention and dedicated services.** There is a desire for respite nurses and support group discussion, in parallel with care onsite.

HUMANIZED CARE

Current Situation

- **One size-fits-all.** Care is often experienced as a uniform protocol – leading to little trust.

Unmet Need

- **Lack of human touch.** Dissatisfaction when services dehumanize people, seeing them as numbers and cash cows.

Ideal

- **People-over-profit care.** Empathetic care customized to each individual. Consistency of services and staff to end life with dignity.

For-Profit vs Nonprofit

NOT a Decision-Making Factor



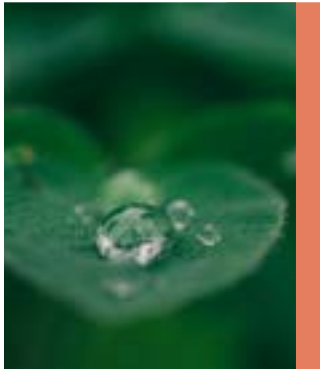
For-Profit Perceptions by Non-Users

RELIABLE CARE

Trust in a steady flow of funding. Many trust for-profit healthcare providers for their perceived reliability and consistent resource availability, often attributed to their funding model driven by profits from patient services, investments, and other revenue streams.

BETTER SERVICES

Enhanced resources, specialized services. For-profit providers are often perceived to have greater access to resources, and therefore to be able to offer a broader range of specialized services, cutting-edge treatments, and high-quality care.



Nonprofit Perceptions by Non-Users

UNSTABLE CARE

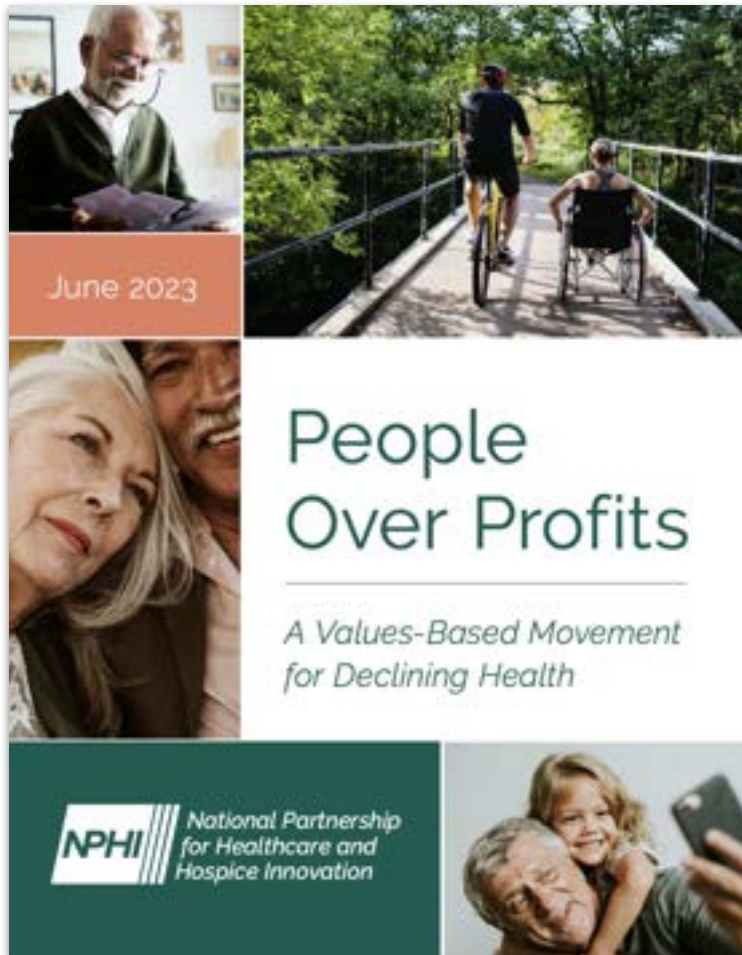
Unfounded funding and quality concerns. Some people are skeptical of nonprofit healthcare providers due to concerns about potential staff shortages and financial viability. The idea of not relying on a steady source of funding seem to scare people from receiving an adequate level of care.

HUMAN TOUCH

People before profit. Nonprofit healthcare providers are often seen as providing empathetic care driven by altruism rather than financial gain. The fact that they chose to work in a nonprofit environment generates the assumption that they will have a more human approach in their care.

03

Blueprint Release



About the Blueprint

People Over Profits: A Values-Based Movement for Declining Health is a field-building blueprint developed in collaboration with Emergence Creative and published by NPHI.

The blueprint seeks to outline the shared values, vision, and expertise of NPHI members, in order to position NPHI as the trusted national authority on declining health. It was developed to help NPHI members tell a unified story about the care they provide in communities across the country.

Personal stories drawn from the caregiver research summarized in this deck were incorporated into the blueprint, alongside original quantitative research exploring perceptions and preferences around aging, serious illness, and death, also conducted by Emergence.

The caregiver research itself contains additional insights that have great potential across a variety of applications.

The Blueprint Release

Released June 6, 2023

- Sent to 100+ NPHI members.
- Press release picked up 300+ times to reach 264.9 million estimated readers.

The policy impact:

- The blueprint includes a series of recommendations, including 3 with direct policy implications.
- The blueprint is being mailed to 100+ members of Congress who sit on healthcare committees.
- NPHI members will be lobbying in-person in September.
- Some members are also sending blueprint copies to their local politicians.



Member Materials: Sharing the Message Across NPHI's Network

Emergence created a suite of materials to assist NPHI members in communicating about their work and leveraging the findings of the blueprint with relevant local stakeholders.

Photo Library/Dos and Don'ts



Marketing Sessions Recap



Messaging Toolkit



Social Media Toolkit



Presentation Template Deck




NPHI Members on the Blueprint in Action



Our CEO and I have reviewed the blueprint and I also sent it to our ad agency to help us to determine how we should best use the information.

- **Anonymous Marketing Director**




We are going to show all our boards — [including] 50+ members — the presentation as information and a teaching opportunity.

- **Anonymous Member CEO**

I really appreciated how the blueprint consolidated so many useful data points all in one place. Just this week, I was looking for a stat, and sure enough, it was in the blueprint. I think the health equity stats are also really helpful.


- **Anonymous Comms Manager**

NPHI Members on the Blueprint in Action



I have highlighted so many things to help us with our messaging and new program development. I plan to share my highlights with the senior leadership team and our executive committee. Thank you for having the foresight to do this work on behalf of the members.

– **Anonymous Member CEO**



For us, the convenience of being able to use the social toolkit through Canva and the specific instructions were great. Just to have a template that we can work with has been very helpful. Also, the provided data and real stories were valuable content that we can use for not only marketing but for grant writing and community education as well.

– **Anonymous Business Operations Member**

An elderly couple is shown from behind, embracing each other on a grassy cliff. The man is wearing a grey jacket and the woman is wearing a dark blue jacket. They are looking out over a scenic view of a coastline with a beach and a bay. The text "Thank you!" is overlaid in white on the left side of the image.

Thank you!