Center for Innovation
& Value Research

Uncovering the True Cost of Healthcare

The Economic Realities of Caregiving

Workshop #3 Learning Report

May 2025

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Uncovering the True Cost of Healthcare

The Economic Realities of Caregiving

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Plain Language Summary

Family members and other unpaid caregivers play a crucial role in supporting loved ones with serious health conditions. However, the financial and personal costs of caregiving are often overlooked, despite their significant impact. These costs include direct expenses, lost income, and emotional and physical strain.

To explore these challenges, the Center for Innovation & Value Research (the Center) hosted a virtual workshop, *The Economic Realities of Caregiving,* on February 26, 2025. This was the third event in a six-part series under the Uncovering the True Cost of Healthcare project. More than 60 people, including caregivers, patients, and researchers, came together to discuss the financial impact of caregiving and ways to improve support for caregivers.

Highlights from the workshop included:

- Christine Freund shared her experience caring for her brother with Huntington's Disease and her mother with lung cancer, discussing the financial and emotional difficulties she faced.
- Dorothy Winningham described the challenges of caregiving for her mother and brother, including the tough financial decisions required to manage their care and the emotional strain that remains today.
- Geri Baumblatt highlighted the career disruptions and financial struggles she experienced while caring for her parents and also presented research on the economic impacts of caregiving.
- Tara Lavelle and Geri Baumblatt presented current research on the economic impacts of caregiving and emphasized the need for more studies.
- Workshop participants discussed various financial and personal challenges, including: out-of-pocket costs for medical and daily living expenses, lost income due to reduced work hours or leaving a job to provide care, and the emotional toll of caregiving, leading to stress, burnout, and health problems.

One important takeaway was that we need better ways to measure how caregiving impacts people financially. Many people who care for a loved one don't see themselves as "caregivers," which means they might miss out on resources and support. Studying the long-term financial and health effects of caregiving can help people and organizations understand the full picture. Going forward, caregivers, researchers, and policymakers need to work together to find solutions that ease the financial impacts of caregiving. When we fully recognize the costs involved, we can create better policies that provide both financial and emotional support—leading to better outcomes for caregivers, patients, and their families.

Uncovering the True Cost of Healthcare is a Center for Innovation & Value Research (Center) project exploring patient-centered economic impacts. We recognize that patients and caregivers are payers in the U.S. healthcare system and our research and decisions need to reflect that.

Through partnerships with patients, caregivers, researchers, and other decision-makers, we are seeking better ways to understand how healthcare costs affect patients and their families.

Summary

Family members and other informal caregivers play a crucial role in supporting patients throughout their health care journey.[a] However, the financial and personal costs of caregiving are rarely measured, despite their significant impact on both caregivers and patients. The Center for Innovation & Value Research (the Center) hosted its third virtual workshop, *The Economic Realities of Caregiving*, on February 26, 2025. This workshop is part of a six-part series for the Center's project **Uncovering the True Cost of Healthcare.**[b]

Grounded in the Patient-Centered Economic Impacts[c] (PCEI) Framework, the workshop explored the following key questions:

- What are the most significant financial challenges caregivers face? How do these vary based on the caregiver's and patient's circumstances?
- What insights do current research provide on assessing the financial impact of caregiving? Where are the gaps, and how can we improve measurement?
- How can a better understanding of caregiving's financial impact lead to better support for both patients and caregivers?

The workshop brought together a diverse group of more than 60 participants[d], fostering a rich and dynamic conversation to identify challenges and opportunities for better understanding of the economic impact of caregiving. In addition, we partnered with four faculty members, each bringing unique expertise and/or lived experience with caregiving:

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[a] Refer to Appendix A for additional resources on caregiving.

[b] This project was partially funded through two Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Awards (#EASCS-24272 and #EACB-32695).

[c] Patient-centered economic impacts are the financial outcomes that patients, family members, and caregivers experience due to health conditions and healthcare treatment. For a full definition and the Framework, see Appendix B.

[d] Refer to Appendix C for a full list of workshop participants.

- **Christine Freund, CSW** – A caregiver for multiple family members, and a member of the project's Community Advisory Board, Christine shared insights on the financial and emotional challenges she faced caring for her brother with Huntington's disease and for her mother with lung cancer.
- **Dorothy Winningham** – An advocate for patients, families, and caregivers and a member of the project's Community Advisory Board, shared firsthand experience navigating the complexities of caring for her mother and brother with multiple chronic health conditions.
- **Geri Baumblatt, MA** – A consultant and expert in patient communication and health literacy, Geri shared her personal experiences caring for both her parents and discussed the need for more research on the impacts of caregiving and the economic challenges caregivers face, particularly on employment.
- **Tara Lavelle, PhD** – A researcher specializing in evaluating the cost-effectiveness of health interventions, Tara shared the current research on caregiver economic impacts and identified the existing major research gaps.

> *"I think each caregiver has their own journey, and we need to ask them what they actually need."*
>
> *– Workshop Participant*

The workshop featured a range of activities designed to explore the economic impact of caregiving from multiple perspectives. Faculty members provided an overview of the emotional and financial impacts of caregiving, blending personal stories, research insights, and considerations to drive a meaningful conversation about the current gaps. Participants engaged in interactive exercises and breakout room discussions. In this report, we highlight learnings from the workshop.

Defining Caregiving and Scope

To anchor the workshop discussion, the following definition was used for context: *informal caregivers provide unpaid care on a regular basis for a family member or friend who is aging, ill, or disabled.*

In 2021, 38 million Americans spent a total of 36 billion hours caring for adults with chronic, disabling, or serious health conditions.[1] While these caregivers are unpaid, the American Association of Retired Persons (AARP) estimates the economic value of this care at $600 billion.[2]

In academic settings, these financial and time-related costs are often referred to as "caregiver burden." While this term is widely used, we chose not to use "caregiver burden" because of its negative connotation, and because many caregivers do not view their loved ones as a burden.

Throughout the workshop, we consistently heard that caregiving looks different for everyone. While it can be deeply rewarding, it can also significantly impact mental, physical, and financial well-being (see Figure 1).

Grounding in Lived Experience

Workshop faculty and participants engaged in a rich discussion on the realities of caregiving and what can be done to better understand the broader impacts on patients, families, and the healthcare system. Participants emphasized that any research approach should start with partnering with caregivers to understand their needs and priorities. To anchor the discussion in lived experience, faculty members – Geri, Dorothy, and Christine – discussed the tremendous impacts caregivers face when caring for a loved one. The impacts discussed (see Figure 2) can be summarized into the domains referenced in the Center's Patient-Centered Economic Impacts[e] Framework:

- Direct Medical Costs
- Non-Clinical Healthcare Related Costs
- Impacts on Caregivers and Families
- Social Impacts
- Ability to Work
- Education or Job Impacts

Figure 1. Word Cloud from Workshop

Participant Exercise: What does caregiving mean to you?

> *"There is a long-term insufficiency (or inefficiency) in how we have set up the entire healthcare system and many of these caregiver impacts are ripple effects of the overall problems with healthcare."*
>
> *– Workshop Participant*

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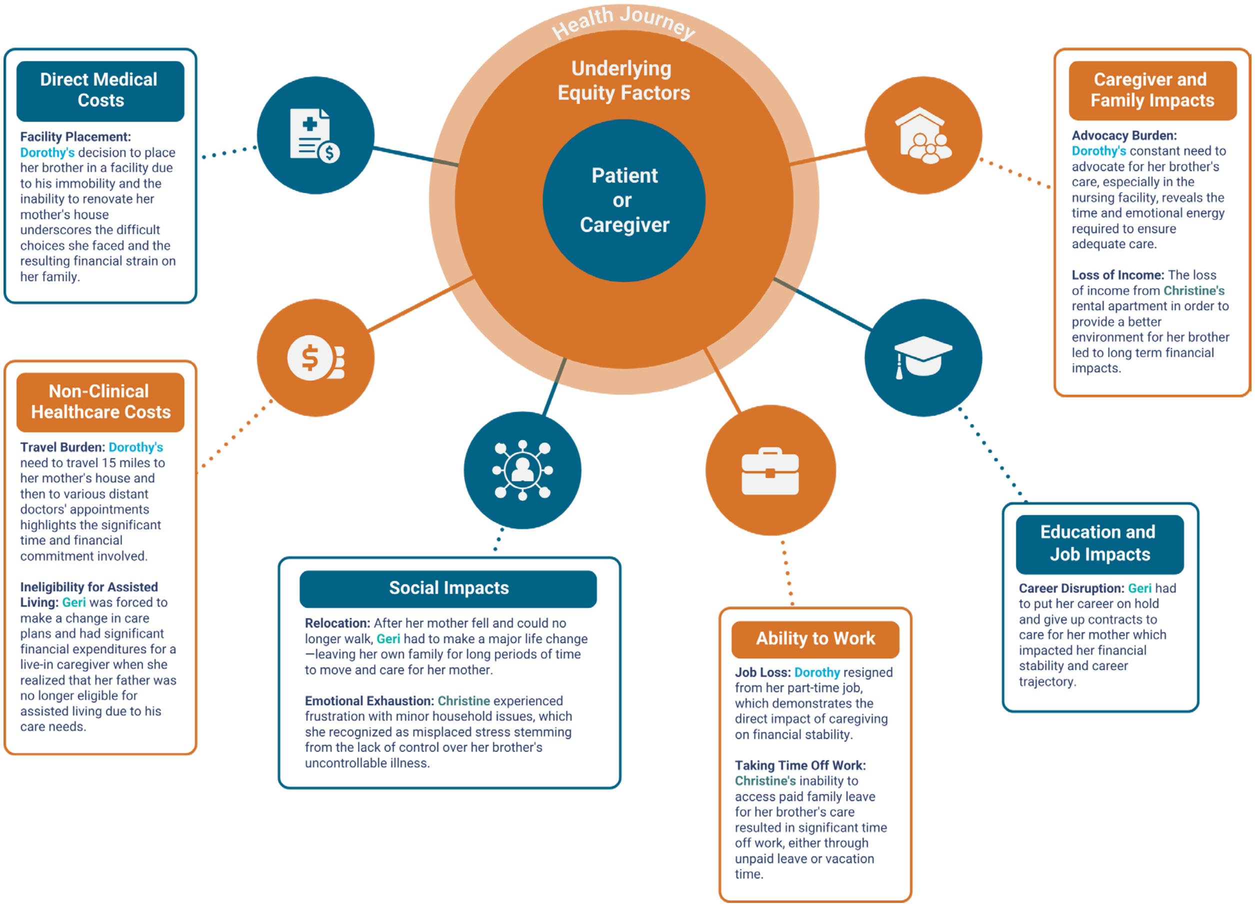
[e] Patient-centered economic impacts are the financial outcomes that patients, family members, and caregivers experience due to health conditions and healthcare treatment. For a full definition and the Framework, see Appendix B.

Figure 2. Examples of Patient-Centered Economic Impacts From the Perspectives of Caregivers



Direct Medical Costs

Facility Placement: Dorothy's decision to place her brother in a facility due to his immobility and the inability to renovate her mother's house underscores the difficult choices she faced and the resulting financial strain on her family.

Non-Clinical Healthcare Costs

Travel Burden: Dorothy's need to travel 15 miles to her mother's house and then to various distant doctors' appointments highlights the significant time and financial commitment involved.

Ineligibility for Assisted Living: Geri was forced to make a change in care plans and had significant financial expenditures for a live-in caregiver when she realized that her father was no longer eligible for assisted living due to his care needs.

Social Impacts

Relocation: After her mother fell and could no longer walk, Geri had to make a major life change—leaving her own family for long periods of time to move and care for her mother.

Emotional Exhaustion: Christine experienced frustration with minor household issues, which she recognized as misplaced stress stemming from the lack of control over her brother's uncontrollable illness.

Ability to Work

Job Loss: Dorothy resigned from her part-time job, which demonstrates the direct impact of caregiving on financial stability.

Taking Time Off Work: Christine's inability to access paid family leave for her brother's care resulted in significant time off work, either through unpaid leave or vacation time.

Education and Job Impacts

Career Disruption: Geri had to put her career on hold and give up contracts to care for her mother which impacted her financial stability and career trajectory.

Caregiver and Family Impacts

Advocacy Burden: Dorothy's constant need to advocate for her brother's care, especially in the nursing facility, reveals the time and emotional energy required to ensure adequate care.

Loss of Income: The loss of income from Christine's rental apartment in order to provide a better environment for her brother led to long term financial impacts.

Caregiver Impacts on Career, Finances, and Health

Across the caregiving stories and research presentation, faculty members and participants highlighted impacts in three main areas: career impacts, direct financial impacts, and caregiver health impacts. The following section highlights some of the evidence and long-term implications shared through caregiver storytelling, research presented by the workshop faculty, and discussions in the breakout rooms with workshop participants. For each section, we identify potential key research questions that could be explored to assess the economic impacts of caregiving.

> *"It probably took me at least a couple years to figure out that I was a caregiver. So, I really wasn't talking to my manager, or planning for things. I was just dealing with these experiences as they came up."*
>
> *– Geri Baumblatt, Workshop Faculty*

Career Impacts

As of 2022, approximately 6.6 million Americans were not working due to caregiving[3], affecting not only families but also employers, who face workforce shortages and productivity challenges. In addition, around 20% of the workforce are caregivers, and within the next five years, 54% are expected to take on caregiving responsibilities.

> *"[My brother] had one day of chemo. I would stay with him for the chemo, and during that time, I was trying to hold down a part-time job, but eventually I had to resign from that."*
>
> *– Dorothy Winningham, Workshop Faculty*

Caregiving responsibilities can lead to presenteeism, absenteeism, adjustments to work schedules (e.g., arriving late, leaving early, or taking time off), and overall job stress. The struggle to balance caregiving with work, especially in inflexible job environments, creates additional financial strain with lost income and reduced long-term earnings affecting caregivers' financial stability. Furthermore, career growth is often impacted, as 48% of caregivers choose not to seek promotions, and 32% have quit a job due to caregiving demands. With an increased percentage of the workforce taking on caregiving responsibilities, employers also face growing challenges in workforce stability such as decreased efficiency and increased turnover rates as more caregivers leave their jobs.

Questions Researchers Could Explore

- How can researchers assist in identifying individuals as caregivers earlier, so they can be connected to meaningful support and services before facing urgent or chaotic situations?
- How does caregiving impact long-term financial security, including retirement savings, career progression, employment, and wealth accumulation?
- What are the physical and mental health impacts of caregiving, and how do they translate into financial impacts (e.g., lost productivity, medical expenses, early retirement)?
- How do employer-provided benefits, policies, and culture change (e.g., paid leave, flexible work arrangements) affect caregivers' financial outcomes and career trajectories?

Direct Financial Impacts

> *"I never even thought of the indirect costs that I had without realizing it – contributing to my 401k, not going for promotion, and those unforeseen costs. When I added up the time I spent caring for my brother, I added it up to over 22,000 hours over 15 years."*
>
> *– Christine Freund, Workshop Faculty*

Caregiving can have a direct impact on a family's financial well-being. On average, family caregivers spend around 26% of their income, approximately $7,200 per year, on caregiving costs. Furthermore, 45% of caregivers report that they're not saving for future health care costs, and instead, they're paying off debt, saving for unexpected expenses, and managing caregiving costs.[4] One study found that this financial strain is greater on certain populations such as Latinos, African Americans, women, those who identify with LGBTQ, and younger caregivers (age 18-39).[5] Most existing caregiver research studies focus on short-term out-of-pocket expenses of specific conditions, missing the longer-term impact and cumulative effects of financial strain over time.[6, 7, 8, 9]

Questions Researchers Could Explore

- How do caregiving responsibilities affect household financial security?
- What are the primary out-of-pocket costs (e.g., healthcare, transportation, paid care), and how do they vary across different caregiving situations?
- How do demographic, geographic, and cultural factors influence caregiving experiences, and financial burdens?
- To what extent do public programs (e.g., Medicaid, Medicare, Social Security benefits, tax credits) mitigate or exacerbate caregiving-related financial burdens?
- What strategies and interventions can mitigate financial hardships for caregivers?
- What datasets currently provide insight into financial burdens of caregiving? What data are needed to address research gaps?

Caregiver Health Impacts

> *"I must have rescheduled some of my basic screening exams six times at this point. My doctor was giving me a hard time, and I was like, 'I had a new emergency with my mom.' Caregivers really do become second order patients."*
>
> *– Geri Baumblatt, Workshop Faculty*

The demands of caregiving make it difficult for caregivers to maintain their own physical, mental, and emotional health. Many times, caregivers face delays in regular screening tests or doctors' visits[10] which can have long-term impacts on health. More than 30% of caregivers continue to provide care for others while suffering from poor health themselves.[11]

Studies have shown caregivers consistently report increased levels of depressive symptoms and mental health concerns[12] and caregivers experiencing depressive symptoms face higher risks of anxiety, substance abuse, chronic conditions, and suicide attempts.[13] Caregivers have issues with sleep and have increased risk of stroke[11] and heart disease.[14]

Questions Researchers Could Explore

- What are the physical and mental health impacts of caregiving, and how do they translate into financial strain (e.g., lost productivity, medical expenses, early retirement)?
- What health care services do caregivers forego due to their caregiving responsibilities?
- What long-term health consequences do caregivers face and what are the associated costs?
- What differences exist in access to financial and social support systems for caregivers? How might they differ in urban, suburban, and rural settings?

Key Considerations

Caregivers are a critical part of our healthcare ecosystem, but their experiences are not fully included in research or decision-making. Measuring the impacts on caregivers in research is essential to understanding the full range of economic impacts that patients and their families experience when facing a serious health condition. Throughout the workshop, the following themes emerged which highlight key factors that researchers should consider when designing studies on caregiving.

> *"The caregiver demographics are constantly changing so it's really important to understand who are these caregivers, and what are their direct and indirect costs, so we can have policies that are addressed for the right people."*
>
> *– Tara Lavelle, Workshop Faculty*

Recognize the Entire Caregiving Network

- Caregiving is often a shared responsibility among family members and/or other loved ones, even if one individual is the primary caregiver.
- To get a holistic view of the economic impacts experienced by caregivers, the entire network of caregivers should be considered.[f]

Expand the Definition of Caregivers

- Many caregivers do not self-identify as "caregivers," and consider their role as part of their familial duty or responsibility.
- This poses a challenge for conducting research in the field but also means caregivers may be less likely to look for and use support services.
- In addition, this lack of self-identification likely results in an underestimation of the true number of caregivers, as well as the financial and emotional impacts of caregiving.

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[f] Consider using an Atlas Care Map to determine who is in your caregiving network: https://atlasofcaregiving.com/caremap/

Consider How Caregiving Roles Shift Based on Who Needs Care

- Caregiving roles can differ among family members.
- For example, caring for a parent may look very different than caring for a child, sibling, or spouse.
- These dynamics are complicated and can sometimes create tension within the family due to unequal workloads, or unrealistic expectations about caregiving responsibilities.

Explore Differences Between Groups in Caregiving Economic Impacts

- Caregiving varies by many factors, including but not limited to health condition, age, race/ethnicity, culture, and geographic proximity.
- Many caregivers are caring for multiple family members. Those in the "sandwich generation" are often caregiving for their older family member or friend, as well as their children or grandchildren which increases the emotional and financial strain.

Examine How Caregiving Can Change Over Time

- On average, caregivers spend 4.5 years and 24 hours per week in their role.[12]
- Caregiving can vary in time span with some caring for loved ones on a short-term basis, while others are involved in long-term capacity.
- Caregiving responsibilities may also shift over time based on changes in the person's health, making it difficult to plan for future responsibilities. This unpredictability can lead to crises when circumstances suddenly change.

Next Steps

Caregivers play a vital role in our healthcare system, supporting both patients and providers as they help loved ones with health challenges. While some research has been conducted to capture the economic impact on caregivers, more studies are needed, particularly on the long-term effects. This workshop highlighted the daily and unforeseen challenges faced by caregivers and emphasized the urgent need for research to understand the full range of economic impacts.

> *“There is no price you can put on the mental strain and worry the caregiver experiences. I had become so involved around caregiving that I became a different person.”*
>
> *– Dorothy Winningham,*
> *Workshop Faculty*

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Appendix A: Additional Resources

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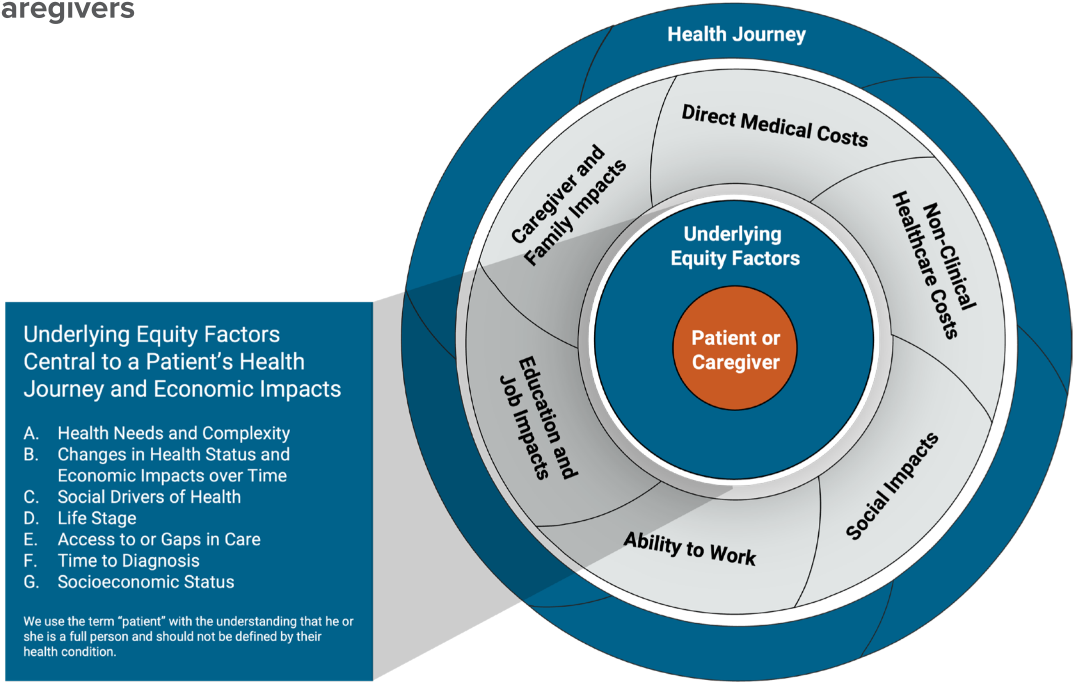
Appendix B: Overview of Patient-Centered Economic Impacts

Patient-centered economic impacts are the financial outcomes that patients[i], family members, and caregivers experience due to health conditions and healthcare treatment. In 2023, the Center and AcademyHealth partnered with stakeholders to produce **A Research Framework to Understand the Full Range of Economic Impacts on Patients and Caregivers**. The framework helps us understand what we mean by "patient-centered economic impacts," or the costs associated with seeking healthcare like time spent going to the hospital for a health emergency, medicine, travel to doctor's appointments, or taking care of family members. Six main areas of patient-centered economic impacts identified include: 1) Direct Medical Costs, 2) Non-Clinical Healthcare Related Costs, 3) Impacts on Caregivers and Families, 4) Social Impacts, 5) Ability to Work, and 6) Education or Job Impacts.

Patients and caregivers must be at the center of understanding these economic impacts, and a person's health journey is foundational to understanding economic impacts – which are often overlapping, complex, and difficult to measure. Further, underlying factors – health complexity, social drivers of health, time to diagnosis, and others – influence the experience of these economic impacts. Appendix B in the Framework includes detailed examples of the kinds of costs that fit into these categories.

Figure B1. An Interactive Framework to Understand Economic Impacts on Patients and Caregivers



Underlying Equity Factors Central to a Patient's Health Journey and Economic Impacts

A. Health Needs and Complexity
B. Changes in Health Status and Economic Impacts over Time
C. Social Drivers of Health
D. Life Stage
E. Access to or Gaps in Care
F. Time to Diagnosis
G. Socioeconomic Status

We use the term "patient" with the understanding that he or she is a full person and should not be defined by their health condition.

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[i] The Center uses the term "patient" to refer to a person who has had an encounter with the healthcare system and has lived expertise in the healthcare system. We do not suggest that a person is their disease or that it is a person's only area of experience or expertise. We use this term in recognition of their lived experiences and the importance of this experience to improving the healthcare system.

Appendix C: Workshop Attendees

We are deeply appreciative of the insights and candor of the individuals who participated in this workshop. We are proud to include a wide range of experts in the field. The project is guided by a diverse Steering Committee and Community Advisory Board of patients, caregivers, researchers, payers, industry experts, and other stakeholders who provide insights, guidance, and co-leadership throughout the project. Individuals with an asterisk "*" by their name are current members of the advisory committees for this project.

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