Center for Innovation
& Value Research

Uncovering the True Cost of Healthcare

Beyond Productivity: Capturing Long-Term Education and Job Impacts

Workshop #6 Learning Report

April 2026

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Beyond Productivity: Capturing Long-Term Education and Job Impacts

Workshop #6

Plain Language Summary

Health conditions can make it hard to work and go to school and, over time, this can have a real impact for patients and caregivers. For example, someone might:

- Miss school or fall behind in classes;
- Take longer to finish a degree or training;
- Cut back work hours, leave a job, or change careers; or
- Miss promotions, get stuck in a job, or shift the type of work a person can do.

These problems can be caused directly by symptoms or treatment. They can also happen because of other problems that come with illness, like the lack of childcare, stress and difficulty paying attention, time spent on appointments, insurance, or other challenges.

The Center for Innovation & Value Research hosted its sixth workshop, Beyond Productivity: Capturing Long-Term Education and Job Impacts, on December 11, 2025, part of a six-part series called Uncovering the True Cost of Healthcare. The workshop brought together nearly 40 participants, including patients, caregivers, and researchers. The workshop talked about the long-term education and job impacts on patients and caregivers. Highlights from the workshop included:

- Darcel Jackson shared what it was like to care for her daughter, Anniyah, who was born with complex medical needs. She described the hard choices her family has had to make to balance caregiving and work. She also shared how much time caregiving can take, including many hours spent on medical visits, insurance issues, and school meetings.
- Patrick Brady and Shireen Hayatghaibi shared early findings from a study at Cincinnati Children's Hospital. The study is testing how to help families manage the transition home after a child's hospital stay. They found that caregivers lose about one week of work time (about $1,100 in wages) during a hospital stay. Many caregivers also continue to lose work time even one month after going home. Parents also reported spending many hours on unpaid caregiving.
- Cristie Travis talked about the important role employers can play in supporting workers who are patients and caregivers.

Serious health conditions can create long-term financial impacts on school and jobs for patients and caregivers. Many of these impacts are easy to miss at first and may show up months or years later. Measuring these "hidden" burdens can help improve the supports that patients and families need over the course of care.

Uncovering the True Cost of Healthcare is a Center for Innovation & Value Research (the 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

The Center for Innovation & Value Research (the Center) convened its sixth virtual workshop—Beyond Productivity: Capturing Long-Term Education and Job Impacts—on December 11, 2025. This six-part series is part of the project Uncovering the True Cost of Healthcare. With nearly 40 participants representing a range of (and often overlapping) perspectives, the workshop explored the economic impacts that patients and caregivers experience related to long-term changes to education and jobs or careers.

Faculty members Darcel Jackson, Manager, Patient and Family Centered Care at Children's National Hospital, Patrick Brady, Attending Physician and Professor of Pediatrics, and Shireen Hayatghaibi, Assistant Professor of Radiology and Pediatrics at Cincinnati Children's Hospital Medical Center, shared their experiences through a caregiver story share, presentation on comparative effectiveness research, and a panel discussion. Cristie Travis, Senior Advisor at HealthCareTN joined the faculty for closing reflections.

This workshop focused on the long-term impacts on patients and caregivers that can result from serious health conditions, which can derail education and work trajectories in ways that compound over time. These impacts can result in lower lifetime earnings, slower career progression, limited job opportunities, and reduced social mobility.

The workshop focused on the following key questions:

- What specific career setbacks, educational interruptions, and losses in lifetime earnings do patients and caregivers attribute to managing their health condition?
- How can researchers effectively measure and quantify the long-term employment and educational trade-offs patients and caregivers make when managing illness?

Workshop participants and faculty engaged in robust discussion through a small group exercise, interactive polls, and Q&A. In this report, we highlight key learnings from the workshop.

Defining Long-Term Job and Education Impacts

> *"As a former caregiver, I just completed my MPH...at the age of 59...delayed by my caregiving role. I'm likely not alone."*
>
> *– Workshop Participant*

Long-term job and education impacts refer to the cumulative, lasting effects that a health condition has on the ability of patients and their family caregivers to participate in, progress through, or benefit from education and employment over time. These impacts can include changes in the ability to build skills, attend and complete school, participate in work, and advance professionally. They may arise directly from treatment or symptoms experienced by the patient, or indirectly through caregiving responsibilities, time demands, financial strain, and structural barriers associated with managing a health condition. Throughout the workshop, participants also identified both individual and system-level impacts as shown in Table 1.

Table 1. Individual and System Impacts Related to Education and Employment

Individual Impacts	System Impacts
• **Job lock** (staying in a job longer than desired to maintain health benefits) • **Lost wages** (missed work, stopping work, shifting to part-time work) • **Reduced productivity** (time and energy spent accessing and navigating care) • **Stalled advancement** (declining or missing promotions due to care demands) • **Foregone entrepreneurship** (when leaving employment means losing insurance) • **Interrupted education** (pausing schooling or dropping out) • **Barriers to re-entry** after a health crisis (time to return to work; altered career trajectory)	• **A health system not designed for families**, particularly those managing complex or chronic illness • **Insurance and care models that overlook household needs** (e.g., accessible housing, transportation), creating added physical strain and work disruption for caregivers • **Workplace policies and benefits that don't match real-life needs**, including limited leave, rigid schedules, and benefit designs that fail to support long-term illness and caregiving • **Limited policy and research attention** to quantifying the problem and testing solutions at scale

The limited research available shows that people with serious health conditions, and their caregivers, face significant short- and long-term impacts on their work and employment. Those long-term impacts are especially severe for those with complex conditions, and workers in physically or cognitively demanding jobs, where symptoms and treatment side effects further impair work performance. Individuals with four or more chronic health conditions are 29% less likely to be employed than those with fewer health conditions. This has a significant impact on people and employers.[1]

Grounding in Lived Experience

To begin the discussion, faculty member Darcel Jackson shared her story as caregiver to her daughter, Anniyah, who was born with medical complexity. Darcel talked about the difficult trade-offs that she and her husband, Marc, made to manage their daughter's medical needs, while juggling careers. The countless hours navigating medical appointments, insurance claims, prior authorizations, and school meetings. At one point she calculated the number of hours required for outpatient visits (not including travel or preparation time) as 404 hours over an 11-year period. In working with 23 doctors in caring for Anniyah, "not a single person in 18 years of her life actually really asked [about] the time investment of caring for her."

> *"Those are the moments that force you to choose, once more, between your child, your job, your education, your income, and quite frankly, your own well-being. Those choices sometimes may feel small in isolation, but inside your body they are not small at all… And over time, those moments become something larger. They become the true cost of healthcare, and what I like to describe as the ledger that no one else sees."*
>
> *– Darcel Jackson, Workshop Faculty*

All too often, Darcel and Marc, had to make difficult choices about how to fulfill their caregiving responsibilities while also managing work. As Darcel shared, *"for us, the deepest and most lasting disruptions often happened in small, invisible moments of everyday life, the moments that force you, over and over, to draft messages explaining why you cannot be where you're supposed be, why you're late, why you have to leave early, why you're missing meetings. You're trying your hardest, but the life you're living, one that others may not fully understand, keeps rearranging your days."*

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[1] Perkins RC, Garabedian LF, Sawicki GS. Exploring the Link Between Job Mobility, Health Insurance, and Health-related Financial Outcomes in People with Cystic Fibrosis. Ann Am Thorac Soc. 2025;22(11):1790-1793. doi:10.1513/AnnalsATS.202503-276RL

Darcel pointed out that while families may not experience these economic impacts as financial transactions in real-time, they are real economic losses that are distributed over time, shaping a family's educational and employment outcomes. For her and her family, this led to:

- Leaving a job or career to focus on caregiving,
- Pauses in saving for retirement,
- Careers being shaped by illness rather than by talent, interest, or achievement.

Together, these changed the future trajectory for her and her husband's life.

Darcel also underscored the importance of valuing the beneficial impacts of interventions and services that support individuals and families experiencing medical complexities: *"If we only count what illness takes, we will miss how the right support can change a family's future, protect opportunity, restore stability, and give back pieces of life that illness tried to take away."*

Research Study Example

Following Darcel's story, Patrick Brady and Shireen Hayatghaibi presented early findings from the GET2HOME Study they are leading at Cincinnati Children's Hospital. This PCORI-sponsored study focuses on patients and families of hospitalized children with complex chronic conditions.[2] The intervention being assessed through a comparative effectiveness research study looks at a bundle of care coordination and discharge activities aimed to reduce readmissions and emergency department visits. It also evaluates the impact on quality of life for the patient, caregiver, and family. With support from PCORI, the research team was able to add in a survey assessing patient-centered economic impacts part-way through the study.

> *"Parent caregivers are really doing an entirely full-time job by caring for their child with medical complexity. And then when we add on to that them having a job, that's really two full-time jobs, so this is really immense. These costs are largely unrecognized in traditional research studies."*
>
> *– Shireen Hayatghaibi, Workshop Faculty*

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[2] https://www.pcori.org/research-results/2022/comparing-two-ways-help-children-complex-chronic-diseases-return-home-after-hospital-stay

The survey included questions surrounding employment such as:

- How many hours did you miss from work because of your child's health problems?
- How many hours did you work?
- How much did your child's health problems affect your productivity while you were working?

Early findings from the study show that parent caregivers lose the equivalent in hours of a full work week while their child is hospitalized, which equates to an average of $1,100 in lost wages. These losses persist even one month after the child leaves the hospital.

The survey also assessed hours spent on informal care to the sick child. Parents reported an average of 81 hours prior to hospital admission, 64 hours at 7-days post-discharge, and remained high at 64 hours 30-days post discharge. These informal care hours are not typically captured in most research studies. Given these impacts, the team is learning that parent caregivers must continually face a constant balancing act of juggling work, caring for their child, and coping with heightened stress of hospitalization. The team's future work will build upon this study to learn about longer-term economic impacts.

Key Considerations

This workshop highlighted the critical disconnect between the reality of patients and caregivers experiencing health conditions and the systems that individuals must navigate during health challenges, including health care, workplaces, and educational institutions. The onus of navigating the health system to access care, juggle the responsibilities of caregiving and work, and maintaining academic pursuits are placed on the individual.

> *"Insightful employers understand that employees bring the context of their lives with them every day to work... You really need to understand what that context is so that you can help your employees when they're at work be fully...as possible and able, around performance and productivity."*
>
> *– Cristie Travis, Workshop Faculty*

Throughout the workshop, participants discussed how long-term education and employment impacts are shaped by both individual circumstances and system design. Yet because these impacts are hard to see in real life—and rarely captured in standard data—patients and caregivers are seldom asked about them in a structured way. There is little data available to understand the true economic impacts on patients and caregivers while experiencing serious health conditions. The discussions brought to light the need to create a feedback loop that uncovers the unseen burdens from the patient and caregiver perspective, to build an "evidence bridge" to measure and recognize the practical economic trade-offs and deliver actionable data to allow employers and policymakers to invest in supports and resources. The workshop presentations and breakout discussions highlighted the following key considerations:

Patient Health Journeys Cause Lifetime Disruptions (Not Only a One-Time Burden)

Health conditions and caregiving reshape education and employment trajectories over time—interrupting schooling, constraining job options, stalling advancement, and shifting long-term earnings and retirement paths.

Hidden Work Drives Downstream Impacts

"Invisible labor" (administrative burden, coordination, appointments, constant recalculation) compounds over time and helps explain later education and job losses.

Start by Asking Questions

There is an inherent tension between the complexity of lived experience and the feasibility of collecting meaningful data. As an initial step, the workshop underscored the value of routinely asking about job and education impacts in both research and medical practice, using measures that are feasible to implement and relevant across stakeholders.

Call to Action

Addressing the long-term education and workforce impacts of healthcare costs requires coordinated action—centering lived experiences, strengthening research, and equipping employers with tools and resources to create more resilient, supportive systems.

Patients, Caregivers, Advocates

- Share your story and lived experience on how your health journey has impacted your job and/or education, as an individual and a family unit
- Track data, if possible, such as missed school/workdays, caregiving hours, and financial impacts, to couple stories with concrete quantitative data
- Normalize asking employers or educational institutions about how they navigate possible work/school disruptions

Researchers

- Co-design research with patients/caregivers to measure what matters to those living with the condition
- Use both retrospective cohorts (to capture decades of impacts) and prospective cohorts (to observe trajectories over time) to understand long-term jobs impacts
- Convert qualitative insights into variables that can inform health economics and outcomes research (HEOR) models and policy decisions
- Measure time burden with enough specificity to support redesign, including separating direct care time from administrative and navigation time (paperwork, scheduling, insurance, coordination)
- Prioritize intervention-focused research that can inform decisions, such as paid leave and job protection, benefits awareness/navigation, flexibility supports, care coordination/telehealth, and financial decision support

Employers

- Actively support benefits navigation, work-life flexibility, and targeted supports during key pressure points of a health journey (diagnosis, treatment, recovery)
- Partner with research organizations to understand needs across stakeholders

Potential Topics for Future Research

- How do patients and caregivers evaluate employers when selecting jobs (e.g., insurance generosity, flexibility, remote options, leave policies?
- How can we characterize longitudinal impacts on education, career progression, and financial well-being for caregivers and families with 25+ years of experience?
- What proportion of lost time is attributable to administrative and navigation burden versus direct care, and which technology-enabled supports reduce that burden?

Conclusion

Many of the themes raised in this session reflect and build on insights from previous workshops. For individuals living with serious health conditions—and those who care for them—the financial impacts, including job and education impacts, are real but often unrecognized in research and practice. These impacts can be harder to discuss than the disease itself. Notably people often do not fully realize the financial impacts of a healthcare condition, whether it be chronic or a time limited event, until much later. That delayed recognition does not diminish its reality. As the final workshop in the Uncovering the True Cost of Healthcare series makes clear, financial burdens experienced by patients and families must be better measured in order to improve the systems and supports that accompany people throughout healthcare journeys.

> *“We have a system…that is not healthcare. We’re in the business of sick care. I would love for us to be in the business of healthcare… promoting health and wellness for the entire family it serves.”*
>
> *– Darcel Jackson, Workshop Faculty*

Appendix A: Additional Resources

1. Society for Human Resource Management (SHRM). Caregivers in the Workplace: Insights from Workers and HR Professionals SHRM. Published April 11, 2025. Accessed January 15, 2026. https://www.shrm.org/topics-tools/research/caregivers-in-the-workplace-insights-from-workers-and-hr-professionals
2. Perkins RC, Garabedian LF, Sawicki GS. Exploring the Link Between Job Mobility, Health Insurance, and Health-related Financial Outcomes in People with Cystic Fibrosis. Ann Am Thorac Soc. 2025;22(11):1790-1793. doi:10.1513/AnnalsATS.202503-276RL
3. Azaroff LS, Woolhandler S, McCormick D, et al. Job Lock and Parents of Children With Cystic Fibrosis. JAMA Pediatr. 2025;179(1):99-101. Published online October 28, 2024. doi:10.1001/jamapediatrics.2024.4435
4. Cystic Fibrosis Foundation. Life with cystic fibrosis requires costly medications and specialized care... Odds for job lock, curtailed employment elevated in families of kids with cystic fibrosis [post]. LinkedIn. Published date not listed. Accessed January 15, 2026. https://www.linkedin.com/posts/cystic-fibrosis-foundation_odds-for-job-lock-curtailed-employment-elevated-activity-7303085695512842245-P_T-/

Appendix B: Breakout Discussion Questions

Goal of the Activity

Generate practical, patient-centered research ideas uncovering long-term education and employment impacts for patients and caregivers.

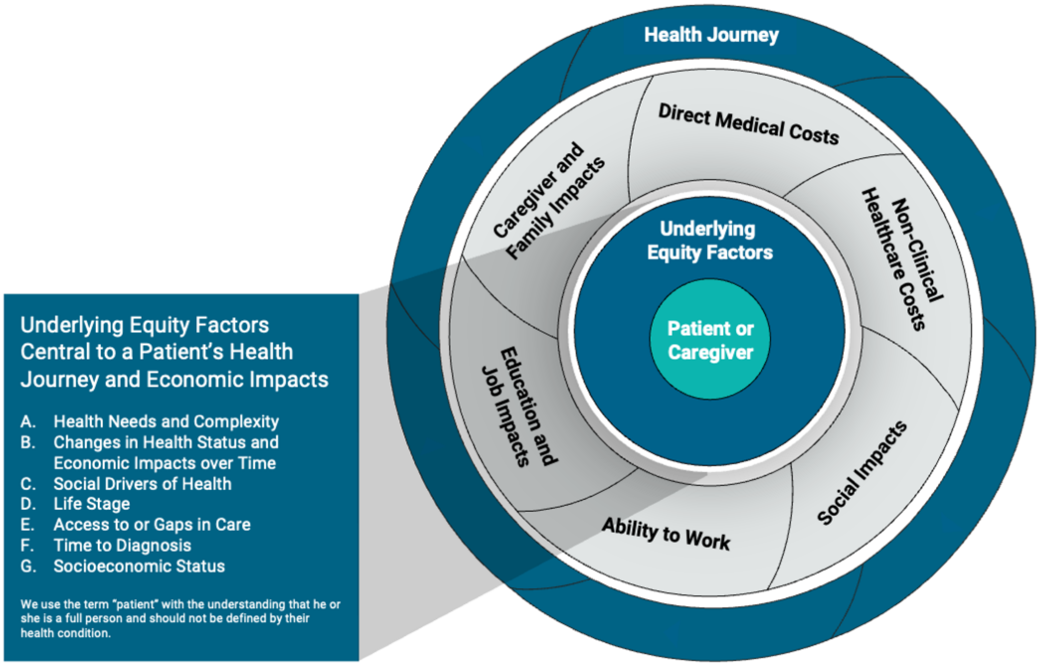
Discussion Questions

1. What long-term job and education impacts matter most for patients and caregivers?
2. How can researchers capture these long-term impacts in meaningful, measurable ways?
3. What interventions could effectively improve long-term impacts in employment and education?

Appendix C: Overview of Patient-Centered Economic Impacts

Patient-centered economic impacts are the financial outcomes that patients[a], 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 man 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 doctors' 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.



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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[a] 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 is a person's only area of experience or expertise. We use them 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.

Center for Innovation & Value Research Team

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- Erica deFur Malik
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- Smita Sanwardeker
- Kat Weinzierl

Workshop Faculty

- Patrick Brady, MD, MSc, Cincinnati Children's Hospital Medical Center
- Shireen Hayatghaibi, PhD, Cincinnati Children's Hospital Medical Center
- Darcel Jackson, Children's National Hospital
- Cristie Travis, HealthCareTN

Participants

- Rachael Akay, University of Colorado Anschutz
- Brenda Amezquita-Castro, UNC-Chapel Hill
- Goran Bencina, Eli Lilly
- Karen Carey, Cystic Fibrosis Foundation
- Brian Dawson, Pennsylvania Rare Disease Advisory Council and The Sumaira Foundation*
- Christine Freund, CAB member*
- Terri Ipsen, The Beryl Institute
- Debra Lerner, Tufts Medical Center
- Stephanie Marshall, The Assistance Fund
- Monica Chau, The Hydrocephalus Association
- Mary Reed, Kaiser Permanente
- Wendy Smith Begolka, National Eczema Association
- Kevin Wake, Uriel E. Owens Sickle Cell Disease Association of the Midwest*
- John Watkins, University of Washington
- Alexandra Zaleta, CancerCare
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