



Uncovering the True Cost of Healthcare

Patient Journey Mapping to Inform Economic Impacts

Workshop #1 Learning Report

October 2024

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Plain Language Summary

Patients and their families face many costs as they get care. These costs can include co-pays, filling a prescription, or missing work to go to a doctor's visit. Some costs happen once. Other costs grow over time. All of these costs are important.

On July 18, 2024, the Center for Innovation & Value Research, known as the Center, hosted a workshop with over 50 people. Attendees included patients, caregivers, researchers, and others. The workshop focused on using a process called **patient journey mapping** to understand costs patients and their families pay.

Patient journey mapping is a process of mapping out what patients and their families experience as they get healthcare.

Highlights included:

- Jae Samuel is a patient living with two forms of cancer. He shared some of the costs he and his family have faced during his cancer treatment.
- Elisabeth Oehrlein is a researcher with Applied Patient Experience, LLC. She talked about how to use journey mapping to explore healthcare costs. She talked about how important it is to work with patients and caregivers to build patient journey maps for research.
- Workshop attendees talked about how they would make a patient journey map. Participants also talked about the importance of trust as part of the patient journey mapping. They talked about how to ask patients and caregivers to tell their story to uncover hidden costs and explore how costs grow or shift over time.

Patient journey maps can show gaps in healthcare and social services. They also often show costs missed by researchers, patients, and healthcare providers.

Different people can use journey maps in different ways:

- Advocates can use patient journey maps to show where patients and families need more help.
- Researchers can use these maps to understand how different ways of providing care and treating health conditions affect patients and families.
- Government agencies, service providers, and others can use patient journey maps to improve care and lower costs for patients and 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

The Center for Innovation & Value Research (the Center) convened its first virtual workshop in a six-part series – *Patient Journey Mapping to Inform Economic Impacts*¹ on July 18, 2024. This series is part of the project [Uncovering the True Cost of Healthcare](#).²

With over 50 participants³ representing a range of (and often overlapping) perspectives, the workshop explored how researchers, people with lived experience, funders, and other stakeholders can use patient journey mapping methods to consider the full range of economic impacts patients and caregivers experience in their research and decision-making.

Workshop Objectives

- Identify respectful and empowering ways to include economic impacts when mapping patient journeys.
- Explore how to determine which financial impacts are most important to include in patient journey maps.
- Discover how patient journey maps can inform research design, interpretation, and limitations.

Co-led by both researchers and people with lived experience, the robust discussion raised important themes about the value and potential uses of health journey mapping to understand economic impacts. In this report, we highlight key learnings from the workshop.

“One can create a rich understanding that goes beyond mere statistics by interweaving personal narratives with economic data. In my view, this approach unfolds through four key stages: empathetic engagement, thematic analysis, economic integration, and gap identification and resolution.

– Workshop Participant

¹ 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 A.

² This project was partially funded through two Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Awards (#EASCS-24272 and #EACB-32695).

³ Refer to Appendix B for a full list of workshop participants.

Grounding in Lived Experience

A core principle of patient-centered economic impacts research is to start with the whole person to understand their lived experience. To ground participants in this concept, the workshop first featured a discussion between Jae Samuel (Jae), patient faculty for the workshop and a person living with multiple forms of cancer, and Elisabeth Oehrlein (Elisabeth), a researcher with Applied Patient Experience, LLC, about some of the costs people with serious health conditions experience.

Jae shared part of his story and highlighted some of the unexpected and downstream financial impacts he has experienced. In the 10 years since he was first diagnosed with [multiple myeloma](#), he recalled:

- **Financial impacts create added pressure on caregivers.** Jae and his family struggled with healthcare costs and everyday costs when experiencing a health crisis. He mentioned his wife's need to maintain health coverage through her employer and the impacts his family experienced when his wife was laid off shortly after one of his health incidents.
- **Crises come in clusters.** Jae noticed that his car always seems to break down just when his healthcare needs go up. Transportation costs, including Uber rides and public transportation add to costs. While living on the fixed income of disability insurance, these added financial burdens are challenging. Another example Jae shared was the intersection of severe weather events and health crises. Living in Louisiana, Jae discussed the difficulties in preparing for potential hurricanes and the financial burden that adds on an already financially stressed family.
- **Mental health impacts for caregivers and family add to economic impacts.** Jae spoke about the lack of mental health services and the out-of-pocket costs associated with accessing mental health care to support him and his family in dealing with the health crises.

Patient Journey Mapping Overview

While journey mapping is used relatively often in consumer research and health research, using journey maps to understand the financial burden patients and caregivers experience is an innovative approach. Elisabeth provided a brief overview of journey mapping and considerations when using this tool to understand economic impacts.

Patient journey mapping seeks to understand how patients interact with the healthcare system by mapping different touchpoints as patients seek care, get a diagnosis, undergo treatment, or manage health conditions.⁴ Patient journey mapping, sometimes called healthcare process mapping, is a broad approach that can be adapted to meet different goals. It can focus on very specific types of care, like emergency room visits or cancer care. Or it can look broadly at all the ways patients interact with the healthcare system.

⁴ <https://webmdignite.com/faq/what-is-patient-journey-mapping>

Often the goal of creating a journey map is to improve patients' experience and satisfaction. Other times the goal is to streamline services or make care more efficient. Traditional approaches to patient journey mapping may or may not involve working directly with patients (e.g., journey maps could be based solely on insurance claims data) (see Figures 1 and 2 for example journey maps).

The National Health Council's [Patient Experience Mapping Toolbox](#) is a valuable resource to support patient engagement during the experience mapping process. Another helpful resource shared was the Patient Focused Medicine Development's [Patient Engagement Management Suite](#).

Table 1 below offers insights for when patient experience mapping may be most useful. Figure 3 provides an example template shared by Elizabeth on organizing economic impacts experienced over time.

- **Adapting patient journey mapping for patient-centered research and decision-making** requires focusing on patients' and caregivers' lived experiences. This approach means taking a more comprehensive and holistic view of both patient and caregiver experiences, from the onset of symptoms through diagnosis, treatment, ongoing management, and desired outcomes. It can be used to document the emotional, physical, and financial challenges faced by patients and caregivers. One way to do this is through patient experience mapping.

Table 1. Examples of When Patient Experience Mapping May Support Patient-Centered Research

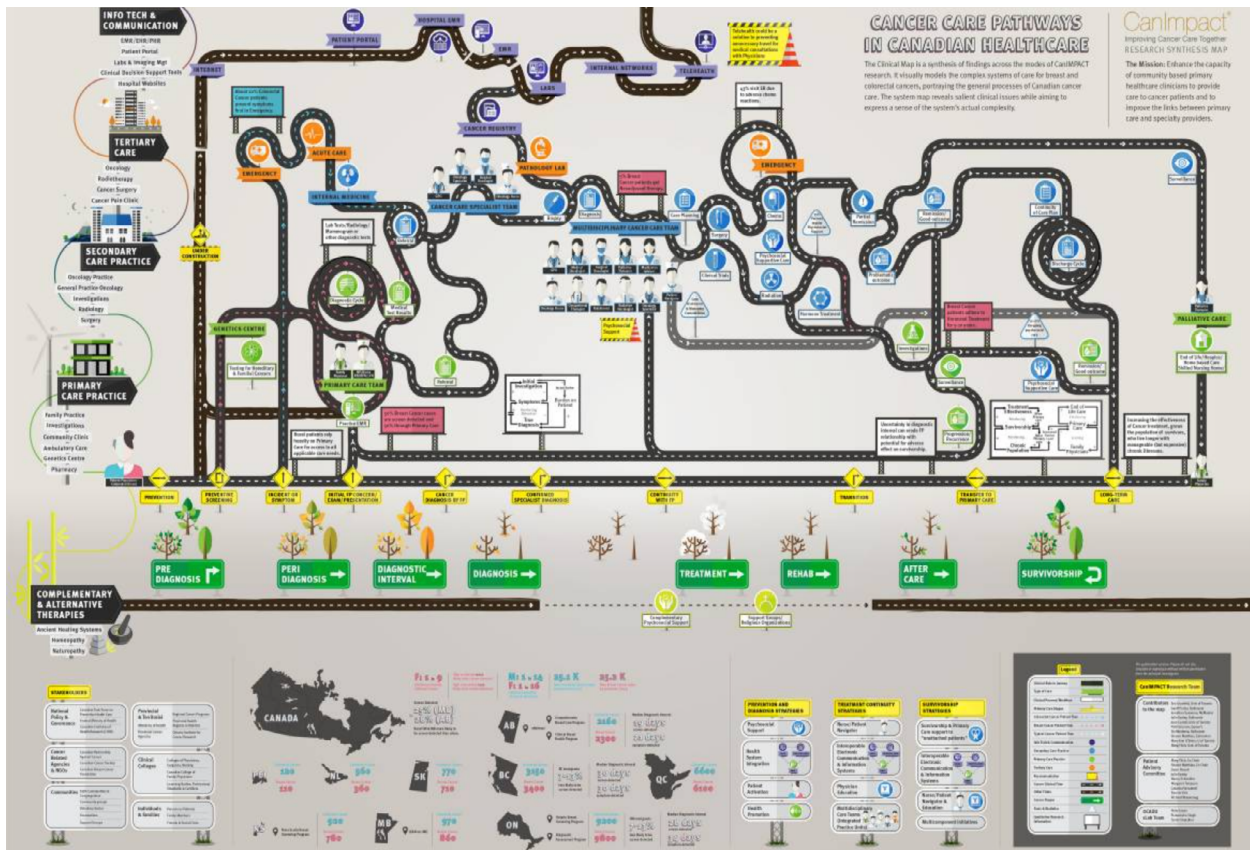
When to Use Patient Experience Mapping in Patient-Centered Research	What Insights on Patient-Centered Economic Impacts the Process can Provide
Understanding the natural history of a disease	Capturing patient experience before being diagnosed, during the diagnostic journey, and while living with and treating a disease can help researchers understand how outcomes and economic impacts change over time.
Identifying comparators that are relevant for patients	Capturing how patients experience different treatment options and the financial impacts of those treatment patterns may inform selection of comparators for research studies.
Selecting which outcomes to measure	Speaking with patients and caregivers allows researchers opportunities to explore the potential trade-offs that patients face when making decisions about their care. Researchers can learn which financial burdens along the patient journey are important outcomes to measure.



- **Patient experience mapping** is an approach to journey mapping that provides a broad and contextual picture that captures a person's experience and impacts over time. Specifically, this covers life before getting a diagnosis, the diagnostic journey, and living with and treating a disease or disability. This approach requires engaging with patients and caregivers through surveys, interviews, focus groups, or other approaches.

- **Shift perspective** from health systems and payers (the traditional perspective used in journey mapping) to the perspectives of people with lived experience, including patients, caregivers, and their families.
- **Bring together data with stories** (known as a mixed-methods approach) to provide context and identify patient priorities for research studies.
- **Unveil the ripple effects** and overlapping nature of economic impacts.
- **Raise awareness of the complex experiences** of people living with serious health conditions.

Figure 2. Example of a Health Journey Map from a Health System Perspective



Source: Jones PH, Shakhder S, Singh P. Synthesis maps: visual knowledge translation for the CanIMPACT clinical system and patient cancer journeys. Curr Oncol. 2017 Apr;24(2):129-134. doi: 10.3747/co.24.3452. Epub 2017 Apr 27. PMID: 28490928; PMCID: PMC5407865.

Figure 3. Exploring Economic Impacts Along the Patient Journey

This excerpt from the presentation slides show how to explore different kinds of economic impacts (the rows) at key points along the patient journey (the columns) to understand how financial burdens change over time.

<p>Consideration: Ask questions in a way that can inform planned economic models. How do costs vary across time? During clinical events?</p>			
<p>Social determinants of health, time & place, health system experiences, misdiagnosis, quality of care, and so on</p>			
	Life before getting a diagnosis	Getting a diagnosis	Living with and treating a disease or disability
Direct medical costs			
Non-clinical healthcare costs			
Social impacts			
Ability to work			
Education and job impacts			
Caregiver and family impacts			

Source: E. Oehrlein, personal communication, July 18, 2024.

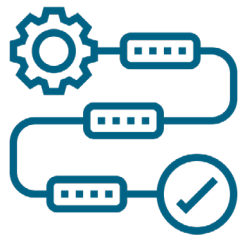
How to Conduct a Patient Experience Mapping Exercise to Uncover Economic Impacts



Clearly define the objective

Be realistic: patient journey mapping can quickly become complicated

- Determine who will use the output, and how. Specify who the target audience is for the experience map.
- Decide whether to focus on a comprehensive or narrow part of the journey.
- Clearly define whose experiences are being represented (e.g., single patient, specific population, or general population).



Determine data sources and methods

Consider if there are potential synergies with other, ongoing research

- Select appropriate methods based on the research objective, budget, and timeline.
- Consider both qualitative and quantitative approaches (i.e., mixed-methods).
- Use existing tools and resources, such as the [National Health Council's Patient Experience Mapping Toolbox](#) or [Connecting Care for Children Experience Mapping: A Tool for Sharing Patient Experience](#).
- Adapt or develop interview questions aligned with study objectives in partnership with patients and caregivers.
- Explore various data sources, including peer-reviewed literature, gray literature (e.g., white papers and reports from patient groups), and patient-generated data.



Develop an analysis plan to map stages across patient experiences

Consider the ripple effects of financial burdens on other aspects of patients' lives

- Identify key stages in the patient journey.
- Organize data collected from interviews, surveys, and other sources to create a coherent narrative.
- Focus on economic impacts, including those identified in the Center's Framework report.
- Map the interactions between patients and various healthcare and social service systems.



Draft the patient experience map

Best practice: co-develop and refine visuals and themes with patient partners

- Create a visual representation of the patient journey, highlighting key stages and economic impacts.
- Use clear and concise language that is easy to understand (i.e., free of technical terms) for patients and other stakeholders.
- Incorporate patient quotes and statistics to provide context and illustrate key points.
- Consider interactive formats (e.g., slides or interactive PDFs) to enhance engagement.
- Collaborate with patient partners to ensure accuracy and relevance.



Disseminate and use the patient experience map

Continuously evaluate and update the experience map as new information becomes available

- Share the patient experience map with patients and other relevant stakeholders, including policymakers, healthcare providers, and patient advocacy groups.
- Use the map to advocate for patient-centered solutions and inform decision-making.
- Ensure the map is accessible for all audiences (e.g., formats that accommodate diverse needs, including text-based versions or audio descriptions for individuals with visual impairment, translation into other languages, etc.).

Key Considerations

The Center's [Framework](#) may help researchers prioritize questions to explore economic impacts as part of patient experience mapping. In addition to using the Framework as a reference, workshop participants and faculty recommend the following key considerations for researchers to effectively apply this approach.

1. Building Trust is Paramount

- Partner with individuals with lived experience to develop interview questions and lead discussions.
- Maintain communication and transparency about the research purpose, how the information will be used, and communicate back findings.
- Be present, an active listener, and ensure individuals feel heard and respected.
- Acknowledge and address any pre-assumed biases that may need to be elaborated on for another person to understand the experience.

"As researchers, we need to approach people with empathy, with care, and respect. Be clear about confidentiality and let people know you want to learn from them to help others. That approach can help because it can help build trust."

– Workshop Participant

2. Uncover Hidden Costs

- Use the Center's PCEI Framework to guide interview questions, leaving room for probing upon story details.
- Pay attention to cues that might reveal hidden burdens, such as changes in lifestyle or difficulty maintaining housing.
- Give concrete examples to help the conversation.

"Economic impacts that we have experienced include modifying the home due to disability, childcare, long-term counseling for the entire family, losing a job, hiring help in the home, traveling to hospitals in other states, having to medevac my husband at a cost of \$13,000 to the hospital when my local doctors refused to treat my husband locally."

– Workshop Participant

3. Explore the Ripple Effects

- Recognize that financial burdens can trigger a cascade of challenges, from missed opportunities to social isolation.
- Use patient experience mapping to uncover these downstream impacts and understand their long-term consequences for patients' well-being.

"But the main thing is that costs continue to go up. Everything is just so much more expensive than it used to be but, the circumstances are still the same."

– Workshop Participant

4. Gain Systems Insights

- Patients often navigate complex healthcare and social service systems. Mapping their journeys can reveal systemic failures, gaps in support, and opportunities for improvement.
- Understanding this knowledge can inform policy changes and interventions to better meet patient needs.

"For those with medically complex conditions, a comprehensive map would need to include multiple systems, services, providers, sources of support, etc."

– Workshop Participant

5. Leverage Patient Experience Maps for Impact

- Use the visual representation of patient journeys to communicate the economic reality of living with a health condition.
- Patient experience maps and collaboration with people with lived experience at the outset of a project can improve research questions, identify different data points, and strengthen the insights from more traditional approaches to research.
- Share these insights with stakeholders, policymakers, and the public to advocate for patient-centered solutions and drive meaningful change in healthcare delivery and financing.

"As a researcher and caregiver, these questions are important, but ultimately will only be useful if we collect data and information to do something to make people's lives better."

– Workshop Participant

Next Steps

This workshop offered an opportunity for researchers, patients, caregivers, and other stakeholders to explore how journey mapping can help uncover the economic impacts patients and their families experience. Patient experience maps created through partnerships among researchers, patients, and caregivers provide one way to incorporate information about patient-centered economic impacts into research studies. Translating the insights gained through patient experience mapping and research on patient-centered economic impacts into health system improvements requires a collaborative process with all stakeholders – most importantly with patients and caregivers.

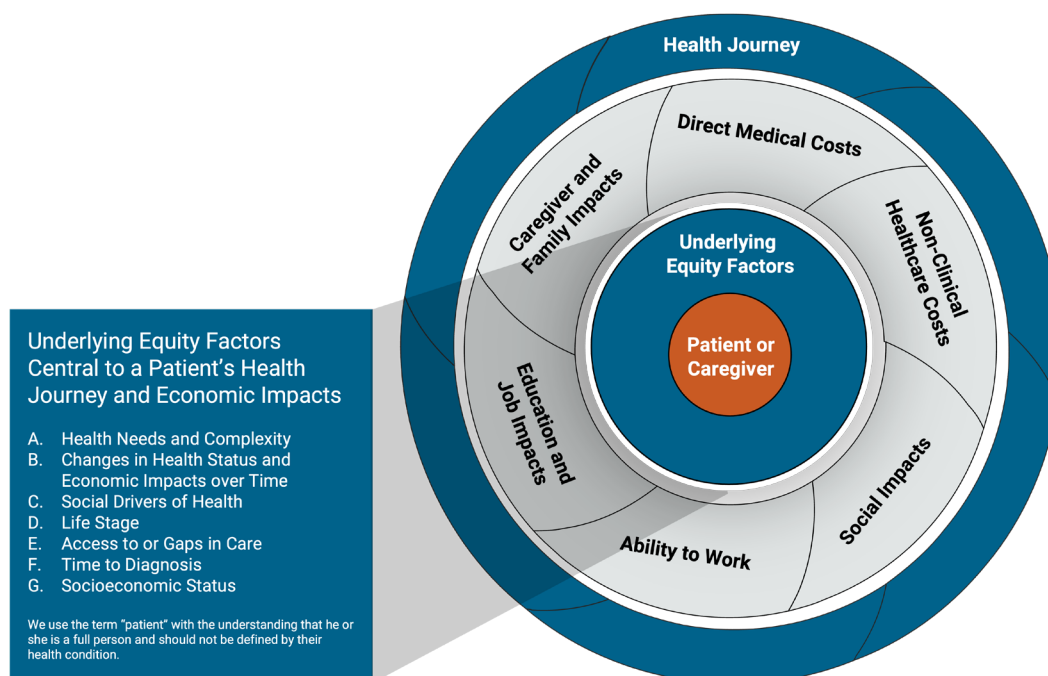
The Center will convene five more workshops to explore additional areas where it is especially challenging to capture patients' and caregivers' economic impacts. More information about these workshops and the project is available online at <https://valueresearch.org/pcei-interactive-workshops/>.

Appendix A: Overview of Patient-Centered Economic Impacts

Patient-centered economic impacts are the financial outcomes that patients⁵, 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 doctors’ appointments, or taking care of family members. Six main areas of patient-centered economic impacts identified include: 1) Direct Medical Costs, 2) 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 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 A1. An Interactive Framework to Understand Economic Impacts on Patients and Caregivers



⁵ The Center uses the term “patient” to refer to a person who has had an encounter with the health-care 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 B: 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 “*” by their name are current members of the advisory committees for this project.

Center for Innovation & Value Research Team

- Ushma Patel
- Melanie Ridley
- Erica deFur Malik
- Ellen Schultz
- Jason Spangler
- Tiffany Huth
- Smita Sanwardeker
- Xanthia Lam

Workshop Faculty

- Elisabeth Oehrlein, Applied Patient Experience*
- Jae Samuel, Patient Advocate*

Participants

- Tina Aswani-Omprakash, South Asian IBD Alliance
- Jamal Brown, Camden Coalition*
- Karen Carey, Cystic Fibrosis Foundation
- Nathorn Chaiyakunapruk, University of Utah
- Andrea Clark, CareQuest Institute for Oral Health
- Elizabeth Cope, AcademyHealth*
- Brian Dawson*
- Karam Diaby, Otsuka Pharmaceutical Companies*
- Tania Dutta, American Institutes of Research
- Omar Escontrias, National Health Council
- Dalya Ferguson, McGovern Medical School at UTHealth Houston
- Elizabeth Franklin, Sanofi
- Christene Freund*
- Laxmi Gannu, Sage Therapeutics
- Lauren Ghazal, University of Rochester
- Beth Gore, OLEY Foundation*
- Gail Graham*
- Allison Gray, Lucile Packard Foundation for Children’s Health
- Stephen Hoy, PFCCPartners
- Anna Hyde, Arthritis Foundation
- Terri Ipsen, Beryl Institute

- Lauren Scannelli Jacobs, Center for Health Care Strategies
- Tania Kamphaus, Foundation for NIH
- Stacey Kowal, Genentech Inc.
- Tara Lavelle, CEVR, Tufts Medical Center
- Cory Lewis, RedMoon Project, Inc.
- Meng Li, Tufts Medical Center
- Barry Liden, USC Schaeffer Center for Health Policy & Economics
- Sally Mabon, Princeton University
- Alexis Malfesi, Centers for Medicare and Medicaid Services*
- Sharon Phares, Center for Biomedical System Design at Tufts Medicine, NEWDIGS
- Beverly Rogers, PEAP*
- Adam Scheffler, Social Worker and Editor
- Silke Schoch, National Health Council*
- Sue Sheridan, Patients for Patient Safety
- Adam Thompson
- Shana Traina, Johnson & Johnson
- Jamie Trotter, National Patient Advocate Foundation
- Joe Vandigo, Applied Patient Experience
- Tyler Wagner, National Pharmaceutical Council
- Kevin Wake, Uriel E. Owens Sickle Cell Disease Association of the Midwest*
- Naomi Williams, Exceptional Living 101
- Dorothy Winningham*
- Shang Xing, Takeda Pharmaceuticals



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