coforma

WHITE PAPER

Using Journey Maps to Better Understand Healthcare Project Stakeholders

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Introduction

Coforma's work is powered by human-centered design, a problem-solving approach that puts people and communities at the heart of all we do. By engaging and embedding patients, caregivers, and healthcare providers into our processes, we are able to understand more deeply and surface solutions for today's most pressing healthcare challenges.

Health is at the center of the human experience. That's why we take a human-centered approach to learning about—and addressing—pain points in care, systems, and technologies. Our solutions are focused on improving health outcomes and experiences so people and societies can thrive. By leading with empathy and learning from all stakeholders, we build trust and gain the wisdom needed to craft creative, informed solutions. We shape solutions that consider the full spectrum of the health experience to support people where and how they need it.

We know sharing health journeys can be uncomfortable. We treat people and their stories considerately, using trauma-informed research practices to better understand each individual's unique experience. Our approach amplifies various perspectives on both sides of design, which helps our cross-functional teams co-create informed, equitable, and inclusive solutions.

Benefits of Using Journey Maps

A journey map visually represents a person's experience accomplishing a goal from beginning to end. It documents the steps they take throughout the experience, the tools and resources they use to complete those steps, the challenges or pain points that pose obstacles, and the opportunities for enhancing or improving the experience. They can also reflect the actions, thoughts and considerations, feelings and emotions, and the worries and concerns that come with each step.

Journey mapping patient experiences allows the viewer to understand what steps are necessary for a patient to obtain the care they need, along with the emotional, financial, and systemic factors that may influence or prevent these steps. Patient experiences differ depending on the illness they are living with and their support, including financial means, personal support, caretakers, location, and access to care. Mapping out the same journey from multiple points of view can help unearth the patterns, discrepancies, opportunity areas, and pain points that occur on the journey.

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Journey mapping isn't limited to a patient. This method can be used to better understand any stakeholder in healthcare, such as providers, payors, support services, and caregivers. It builds empathy and understanding by allowing viewers to comprehend the whole human experience associated with seeking or providing healthcare.

This kind of community engagement is crucial in policymaking, as well. Engaging patients, care providers, payors, caregivers, and other stakeholders ensures that policies reflect the needs of those they are intended to serve. By putting this work in front of policymakers, they are given tools to advocate for policy changes that can benefit the communities whose lived experiences we are telling.

Journey maps are also an important tool to prevent top-down decision- and policy-making, which may overlook the concerns of marginalized groups. When policymakers include community members' voices, this builds trust and stable policy initiatives. Incorporating the lived experiences of patients can identify improvements to government services and interagency efforts toward better care.

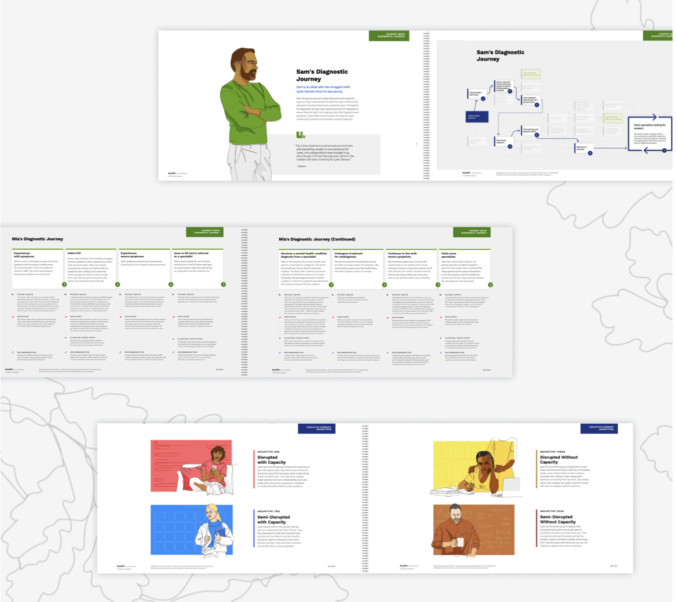
Coforma's Approach to Journey Mapping

Like everything Coforma does, our approach to journey mapping is human-centered. We create journey maps by engaging and co-creating with the communities these maps represent, ensuring their voices are heard at every step. These processes are iterative, collaborative, and inclusive, placing people at the center of their creation. This understanding allows us to make informed recommendations and decisions about better-designed healthcare experiences.

Journey maps can also be used at the software implementation stage of solutioning to increase team alignment, uncover user stories, and aid in the personalization of content. Regardless of the stage, all of our journey maps are informed by empirical evidence, and built to be tested and iterated upon. We develop living artifacts to keep the user in mind and understand their needs, emotions, and obstacles.

Past Work: Four Journey Map Examples

Lyme Disease Patient Journeys



Due to a wide variety of symptoms, people with Lyme disease are often misdiagnosed, overlooked, and not taken seriously. The degree of alarm and confusion about such a long-standing public health issue has become detrimental to Lyme patients' outcomes and diagnostics' progression. This stagnation leaves healthcare professionals with limited resources and tools to accurately diagnose and support patients.

Coforma was engaged to support the LymeX Innovation Accelerator (LymeX), leveraging our expertise from a human-centered design perspective and through the lens of the people in the Lyme community. In partnership with the Department of Health and Human Services (HHS) and the Steven & Alexandra Cohen Foundation, we conducted extensive desk research, interviews, and HCD workshops to surface the problems patients and their caregivers face in getting a diagnosis and treatment for Lyme. We iteratively refined the Lyme archetypes, mapped patients' diagnostic and treatment journeys, synthesized insights to uncover the opportunities that exist to improve patient experiences, and validated the key issues identified by the Lyme community.

Analyzing these journey maps might inform a range of policy decisions to improve diagnosis, patient care, support, as well as public health needs. We learned that the diagnostic process is crucial for patients with Lyme disease but can be lengthy and traumatizing. A possible policy recommendation would be to increase investment in research to develop more accurate and accessible diagnostic tests.

Developing and mandating provider training in Lyme disease is another recommendation, with an emphasis on misdiagnosis, diagnostic criteria, and treatment options. Public health awareness of Lyme disease and what to look out for, as well as preventive measures may also be warranted. Policy experts within local health departments can develop campaigns to promote public education about Lyme disease. Existing public health campaigns on tick exposure, control, and prevention can be augmented to include information on Lyme disease.

The journey maps also showed us that some treatments are not covered by insurance and can become a cost burden for patients—especially long-term antibiotics and symptom management techniques. Policy experts can recommend that government-sponsored health insurance and private insurance provide coverage for these treatments, since this will prevent financial hardship for the patient and will potentially result in cost savings downstream.

Sickle Cell Disease Patient Journeys

HHS sought to respond to a nationwide demand for population-level Sickle Cell Disease (SCD) surveillance data and other data to support better treatments and healthcare options for people with SCD. They needed a partner to conduct several levels of patient-centered research, extract cross-discipline insights by cutting across work silos, and create a platform to begin addressing the sickle cell community's needs and concerns.

health+ Sickle Cell Disease | CTO | OMH

Human-Centered Design Report

coforma | June 2020

Opportunity Areas

1. SCD care is difficult to access
   - Healthcare lacks proper provider training, specialized clinics, and non-opioid treatments
   - Patients are stigmatized as drug seekers in healthcare
   - Access to treatment is compromised by barriers to primary care and cost
   - Patients are often skeptical of healthcare providers
2. ER is a last resort for patients
   - Patients fear being accused of drug seeking
   - ERs often aren't familiar with SCD protocols
   - Adult ERs are busy, with long wait times
3. People with SCD struggle with transition to adulthood
   - Coordinating care independently is challenging
   - Young adults lack understanding on how to secure proper health insurance
   - Hand-off from caregiver to young adult patient is insufficient
4. "Trial and Error": Patients bear the burden of individualizing their care plan
   - Traumatic events are triggers to learn
   - Non-prescribed treatments are a common recourse
   - Patients develop communication strategies to negotiate with providers
   - Patients develop complex financial and health insurance tactics to cover care
5. Patients plan their lives around unpredictability of SCD
   - Emergencies cause emotional trauma in patients and their loved ones
   - Patients anticipate emergencies in all occasions
   - "Invisible disease": isolation, stigma, and lack of understanding at work and school
   - Patients plan careers and even relocate to maximize access to SCD support
6. SCD care requires complex support networks
   - Family is preferred support—but it's often not available
   - Community-based organizations, social media provide solidarity, education, and services
   - Patients wish they could be more independent

Living with SCD as a Child

Caregivers bear the burden of all care coordination, decisions, life interruptions, and more

Living with SCD as a Young Ad

SCD Archetypes

The patient journey map for the emergency room experience outlined the process and experiences of a typical SCD patient experience–from crisis onset and arrival at the ER through evaluation and hospitalization.

The patient journey maps uncovered experiences ranging from bias and lack of SCD experience to inappropriate testing in the ER, insufficient care, and pain management. To address the lack of SCD experience, policies could be developed to include comprehensive education at the curriculum level in medical schools or nursing programs. By working with medical education stakeholders, the required training could be tailored to include SCD testing, pain management, and long-term care for SCD patients. Policymakers could also advocate for health insurance programs to cover care navigation for SCD patients, and stable and sustained funding for social workers and care coordinators to navigate the complex care for SCD patients.

Tribal Patient Journeys

Indian Health Service decision-makers wanted to understand how healthcare technology could better meet the needs of American Indian and Alaskan Native (AI/AN) patients. Our goals were to contextualize the unique functional needs of Health IT for the Indian Health Service/Tribal/Urban Indian health system environment in a way that would help the government and Congress understand the needs and challenges of AI/AN patients.

The patient stories we documented in our work reflected the health disparities affecting AI/AN community members (diabetes, high-risk pregnancy, substance abuse, and more). They also reflected the many barriers community members face getting the healthcare they need (poverty, distance from urban centers, etc.) and unique aspects (eligibility, difficult access to referred care, and more) related to accessing care. We grounded these stories in the patient's journey. While staff were considered the primary users of the

Health IT system we were assessing, we wanted every choice we made to prioritize the patient's needs.

The journey maps we created capture a wide range of roles, processes, and situations learned from the field, and convey as many requirements as possible while keeping the information meaningful and concise.

COVID-19 Patient Journeys

Understanding the COVID-19 journey through people's lived experiences helps patient advocates, policy experts, healthcare providers, government personnel, and others identify and implement meaningful solutions that improve COVID-19 education, prevention, diagnosis, and treatment. Our Long COVID Human-Centered Design Report highlights the testing and diagnosis experience of COVID-19 through the patient lens by including the following:

- Social-ecological framework
- Journey maps detailing testing and diagnostic experiences, including triggers, pain points, and enablers
- Themes demonstrating prioritized, data-informed groupings outlining the biggest pain points for patients
- Opportunity areas for the highest-impact solutions

This report and its journey maps of patient experiences were mentioned as a resource in a 2023 Biden-Harris Administration Fact Sheet detailing the government's response to Long COVID. Under the section titled *Advancing the Nation's Understanding of Long COVID*, the report was noted to provide insights to "focus attention and interventions in areas that matter the most to the community, as articulated by patients and those with first-hand, lived experience with Long COVID."

The journey maps and the experiences of patients testing and receiving care for COVID-19 provided information that could also influence policy initiatives to:

- Address critical access points
- Identify pain points, gaps in care and access, and opportunities for improvement within the healthcare system
- Help inform whether expanded access to testing sites is needed, or whether patients in medically underserved areas (e.g., rural communities and lower-income neighborhoods) are facing barriers to care
- Increase testing availability, incorporate use of mobile testing units, or increase insurance coverage for home testing options
- Develop programs to address Long COVID, including specialized care, research, rehabilitation services, as well as government-sponsored health insurance coverage of care navigation and services

A Closer Look at Long COVID Journey Mapping

The Long COVID Human-Centered Design Report was published in April of 2022. It aimed to elevate what is often underrepresented in Long COVID statistics, scientific literature, and policy making—the narratives and expertise of people with Long COVID and what they want and need to live better, healthier lives.

From the start, Coforma worked closely with people and communities impacted by Long COVID. As active participants, they informed our research plan, shared their experiences and expertise with us, reviewed our draft findings to ensure they were accurate and representative, and recommended solutions.

The report, a result of this process, includes an exploration of how and why the impact of Long COVID varies from person to person, the reasons for which have the potential to increase health disparities between peoples and communities. The symptoms of Long COVID can be mild and barely perceptible, or they can be ever-present and wholly debilitating. However, it is not simply the severity of Long COVID and the conditions associated with it that influence Long COVID's impact on someone's life, but a range of social determinants of health.

In the discovery phase, we recruited a diverse community of individuals to learn alongside, including people with Long COVID, their caregivers, healthcare providers, advocates, and other subject matter experts. We conducted outreach using a variety of strategies: conversations with Long COVID advocacy organizations, including Survivor Corps and Body Politic; social media, including Instagram, Facebook, Reddit, and Twitter; through the networks of our partners at HHS; and through organizations with deep relationships in various communities, including the Tanana Chiefs Conference and the California Center for Functional Medicine.

After conducting desk research to review existing white papers, news articles, and reports on Long COVID, we initiated a series of four discovery workshops with people with Long COVID, caregivers, health care providers, advocates, and other subject matter experts. Their expertise and input informed our subsequent research plan and areas of inquiry.

We then employed a range of research methods to ensure an accessible, comfortable experience. These included 60-minute, semi-structured, remote interviews; audio diaries; and virtual postcards. We engaged over 60 people with Long COVID, caregivers, health care providers, advocates, and other subject matter experts.

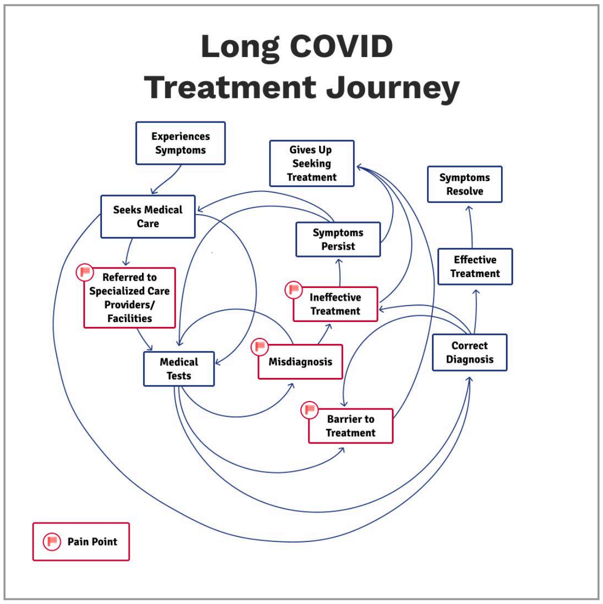
Research focused on deeply understanding the experiences of identifying, diagnosing, and treating Long COVID; the extenuating impacts of Long COVID on lives, livelihoods, and communities; support and assistance for people living with Long COVID, caregivers, and care providers; perceptions and attitudes about Long COVID; and bright spots, opportunities, and aspirations for improving the quality of life and care for people with Long COVID.

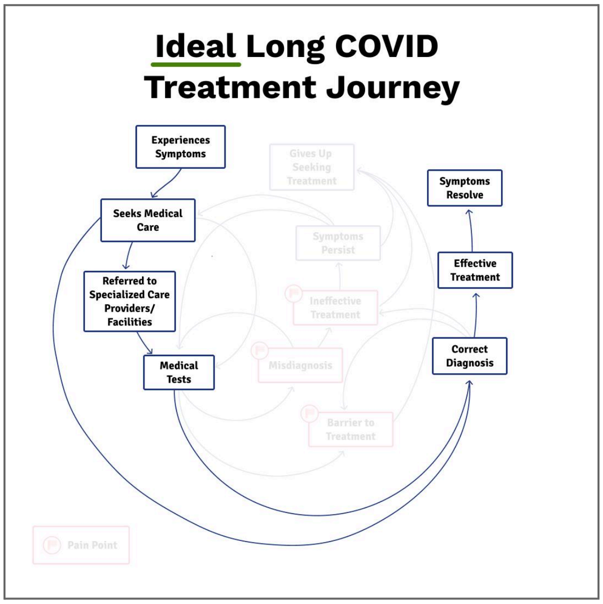
In the ideation phase, we coded and analyzed interviews to identify themes and trends across participants' lived experiences. Using this information, we began to chronologically organize the shared experiences of our participants and create a journey map. One of the challenges our team faced was how to streamline and organize the information so someone with no prior knowledge could understand it while still capturing the complexity and difficulty of the journey itself.

We created a map that shows the many pathways to seeking treatment, including a path that ended with giving up because treatment was unobtainable. To reinforce the difficulty of the actual journey, we also created an ideal journey. Juxtaposed with the ideal journey of a person with Long COVID, the actual journey highlights the large discrepancies between the ideal and actual states. This unique view allowed policymakers to see how current policy was addressing the needs of patients. The journey map used patient experiences and pain points to highlight discrepancies and opportunities to improve existing policies or implement new, data-driven solutions.

Once we had a draft we felt represented the experiences of the folks we interviewed, we re-engaged them for their input. We provided our draft versions of the actual journey and ideal journey maps to our participants and invited them to critique the maps in the ways most accessible to them. Participants were invited to give us their feedback via their preferred communication channel: another series of 1:1 interviews, online workshops with multiple participants, and or print-ready versions of the maps so they could print, mark up and send back to us. We took all feedback into consideration and revised the maps until it was all incorporated into the journeys. The resulting ideal and actual maps were a collaboration between Coforma and the community we were serving.

Simplified Ideal Journey Maps





To view the full journey maps, please check out the Long COVID Report online.

Conclusion

Journey mapping is a powerful tool for engaging and understanding healthcare project stakeholders. As part of an engagement plan, journey maps capture diverse perspectives and empower individuals to actively participate in the decision-making process. They also allow project teams to clarify and align on what they are building and offer potential cost savings by ensuring a team is focused on the right solution.

Journey maps are also effective tools for community engagement and policymaking. Capturing the experiences, challenges, supportive points, and pain points as individuals or communities navigate the healthcare system allows for patient voices to be included in policy decisions and can help create a system that addresses the actual needs of patients and gaps in care. In policymaking, journey maps inform the design, implementation, and evaluation of improved policies that are inclusive and aligned with patient needs, compared to existing policies.

By utilizing journey mapping in healthcare projects and integrating them into policy development, healthcare-based solutions and policies can be more human-centered and data-driven, which will ultimately lead to improved health outcomes.

Benefits of Partnering with Coforma

Coforma is a leading digital services firm that helps our partners deliver inclusive, modernized services to the public that improve our world.

With more than 170 employees, we work closely with our partners to craft creative solutions and build technology products that improve people's lives. Specializing in design, research, engineering, policy implementation, product management, strategy, and delivery, we've honed a modern, agile, user-centered approach that elevates human needs through thoughtfully designed systems and products.

We support the entire delivery cycle for products and services. From ideation to go-live, we center people's diverse needs to help you craft experiences, transform products and services, and ensure success.

Coforma is a minority-owned small business, certified as an 8(a) small business by the Small Business Administration (SBA) and as a Service-Disabled Veteran-Owned Small Business (SDVOSB) by the Department of Veterans Affairs (VA).

Industry Leader with a Strong Record of Success

Coforma has supported state and federal government clients and nonprofit organizations in improving access to quality healthcare, connecting families in crisis at the southwest border, enhancing Veteran care, providing greater access to civic tools, improving the federal employee retirement experience, and increasing equity across digital services access.

We believe in the power of small, diverse teams to collaborate and get things done. We co-create human-centric, ethical, accessible digital services and customer experiences that help people live happier, healthier lives.

Furthermore, Coforma demonstrates its commitment to advancing health policy by growing its dedicated health policy team, which underscores a strategic focus on shaping effective and informed policies.

If you have a healthcare problem we can help you solve, please reach out to us through the contact information listed below. We look forward to the opportunity to make a difference together.

Recent Awards

- SECAF Special Recognition Award (2024)
- OrangeSlices Elev8 GovCon Honoree (2023, 2024)
- BuiltIn’s Washington, DC Best Midsize Places to Work Award (2024, 2025)
- Northern Virginia Chamber of Commerce Government Contracting Distinguished Service Award Winner (2022), Government Contractor of the Year $25 to $75 Million Award Finalist (2024)

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