

Cancer Life
reiMaged:
The CaLM Model
of Whole-Person
Cancer Care



Co-designing a model with patients, survivors, and the community

Christina is 35 years old and has been living with metastatic colorectal cancer for the last several years. She is bright, vivacious, and has an edgy honesty about her. Our team first met Christina in 2017 when she responded to an opportunity to be part of an “experience group”—a type of focus group convened by the Value Institute for Health and Care at the Dell Medical School—that allowed us to learn in depth what life is like for patients living with certain medical conditions or disease. At the time, our team was in the process of building a new model of cancer care. Christina had already undergone five surgeries, four rounds of chemotherapy, and three rounds of radiation. She was receiving treatment and care at a cancer center in Houston, Tex.; but, with a young daughter, a husband, and a full life in Austin, Tex., traveling for treatment on top of coordinating care with multiple specialists was disruptive and stressful for Christina and her family. In discussion, she spoke with transparency and clarity about her cancer journey; the experience of coping with cancer in her 30s; and, most important, her thoughts on re-designing the cancer care system to better serve people dealing with cancer in the midst of life’s complexities. In March 2018,

The CaLM model is designed to deliver cutting-edge cancer therapies in coordination with psychosocial and palliative care. This interdisciplinary, team-based approach to care prioritizes survival and supports everyone’s capability, comfort, and calm as they fight cancer.

Christina became the first member of the Patient and Family Advisory Board we developed to guide the design of a new model of cancer care. In spring 2019, she transferred her care to the Livestrong® Cancer Institutes at UT Health Austin, becoming one of our earliest gastrointestinal oncology patients.

Keep CaLM and Transform Care

In our current healthcare system, cancer care delivery is often fragmented. Patients and caregivers face many challenges, including providers who do not communicate effectively; disjointed, uncoordinated services that do not address all of their issues; and fragmented, costly systems of care.

In the traditional model of cancer care, providers prioritize the delivery of medical services and disease treatment, with the social, emotional, spiritual, cultural, and financial aspects of care often considered ancillary. In fact, many patients are referred to external community resources to receive these comprehensive care services, with scheduling and coordinating appointments falling on the patient and/or caregiver. When these services are not provided in coordination and communication with the patient's medical treatment team, care can become further fragmented. Patients often have limited familiarity with supportive care services, and the goals for care within each specialty may not align, which can result in conflicting guidance and/or treatment for patients. Bottom line: Navigating a cancer diagnosis can be the equivalent of a full-time job. It can bring chaos to patients' daily lives, which can make working, social activity, and daily activities difficult to manage.

Further, for many patients today, cancer is becoming a chronic disease. This is very good news. At the same time, too often cancer care delivery is focused on high-acuity medical decision making. Patients can feel as though they are “living from scan to scan,” relying heavily on oncologists to drive their care. However, oncologists are often unequipped to address emotional, social, and practical issues. This care model does not optimize an individual's ability to live a resilient life.

The mission of the Livestrong Cancer Institutes—a collaboration between the Dell Medical School at the University of Texas at Austin and the Livestrong Foundation founded in 2014—is to radically improve the individual's cancer experience and quality of life, revolutionize cancer treatment, and re-invent the way patients are cared for. Central to our approach is the creation and operationalization of the CaLM Model of Whole-Person Cancer Care™. Cancer Life Reimagined (CaLM) is a comprehensive, clinical, and supportive ambulatory care model that provides “wraparound” care for patients and caregivers in all phases of the cancer continuum.

Livestrong Cancer Institutes set out to build a model that treats the mind, body, and heart, as one entity. The CaLM model is designed to deliver cutting-edge cancer therapies in coordination with psychosocial and palliative care. This interdisciplinary, team-based approach to care prioritizes survival and supports everyone's capability, comfort, and calm as they fight cancer.

Building the Foundations of CaLM

The Livestrong Cancer Institutes use the National Academies of Science, Engineering, and Medicine's definition of patient-centered care, which is “respectful of and responsive to individual patient preferences, needs and values, and ensures that patient values guide all clinical decisions.”¹ The CaLM concept draws from decades of research and advances in the fields of psychosocial oncology, palliative care, integrative oncology, and cancer survi-

vorship. In essence, CaLM is an oncology medical home approach that integrates high-acuity, sub-specialty clinical cancer care with comprehensive, ongoing supportive care. Patients receive best-in-class cancer treatment that encompasses a suite of coordinated supportive services to care for the whole person and their loved ones. CaLM is designed to:

- Optimize the patient experience and outcomes
- Address the unsustainable financial future of cancer care
- Create a scalable strategy to use providers efficiently
- (Ultimately) attain cost savings for the patient, the payer, and the system.

The CaLM model values emotional, social, financial, and practical care equally with clinical services delivered to treat the disease.

In developing the model, we leveraged the work of leading oncology organizations, including the American Society of Clinical Oncology, the American College of Surgeons Commission on Cancer, the National Cancer Institute, the American Cancer Society, the Cancer Support Community, and Livestrong Foundation—all of which have paved the path in improving cancer care. The CaLM model is heavily influenced by the work that our philanthropic partner, the Livestrong Foundation, executed in determining the essential elements of survivorship care,² particularly its 23 elements of patient-centered cancer care.³ The CaLM model builds on these elements through the implementation of strategies, programs, and interventions that operationalize each element in the clinical setting (see Figure 1, right). The CaLM model is also anchored in several evidence-based models of care:

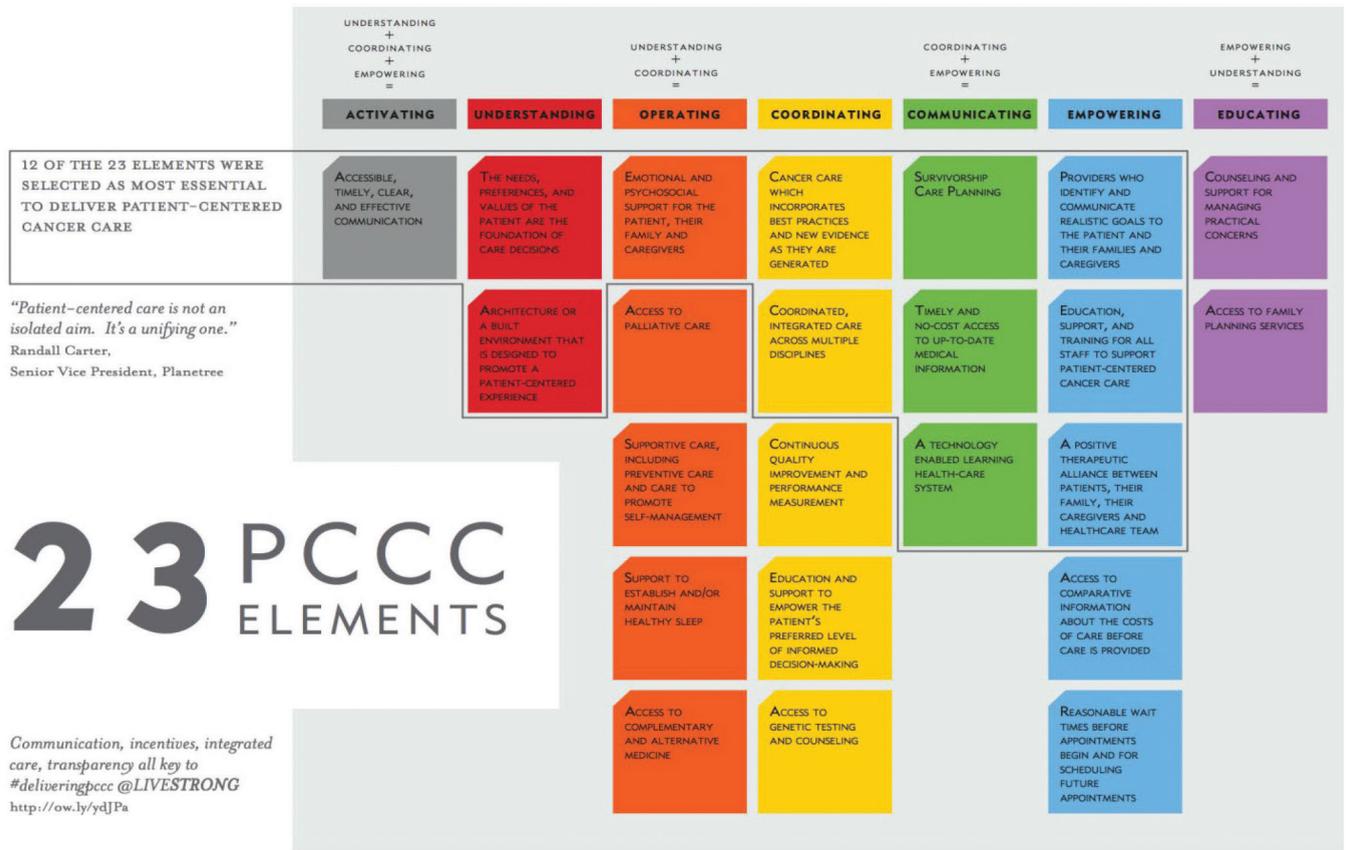
- The National Academy of Medicine's 2013 report *Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis*¹
- The work of the Agency for Healthcare Research and Quality and John Sprandio, MD, on the oncology patient-centered care medical home model⁴
- The collaborative care model, developed jointly by the American Psychiatric Association and the Academy of Psychosomatic Medicine⁵
- The Robert Wood Johnson Foundation and MacColl Center for Healthcare Innovation chronic care model.⁶

Co-Designing the Model

To kick off the design process, in 2017 we established several cross-functional community work groups at the Livestrong Cancer Institutes, including one group focused solely on patient-centered support. Composed of administrators and clinicians from other cancer programs in the Austin area, leaders from local and national non-profit cancer patient support organizations, researchers from the University of Texas, and patients and survivors from the central Texas community, these groups met quarterly for one year. Participants collaborated to identify the ideal components of patient-centered cancer care and discuss what an optimal care delivery process would look like.

During this same time frame, we also embarked on a local and national “listening tour,” visiting more than 35 cancer programs, meeting with social workers, oncologists, and palliative care teams to:

Figure 1. The Essential Elements of Patient-Centered Cancer Care



1. Understand existing resources that we could leverage.
2. Identify perceived service gaps in patient-centered care.
3. Build partnerships for our referral network.

In May 2017 we convened a half-day town hall attended by 80 representatives from local cancer support organizations. We led participants (many of whom had never worked together before) through a series of interactive discussions to help identify service gaps and brainstorm solutions. These conversations not only validated some of our team’s ideas but also helped us define what the CaLM model needed to do differently. For example, though some clinics were using interdisciplinary care teams, patient care was still primarily directed by a physician. We wanted to create a model that gave equal weight to the voices of all those involved in the patient’s cancer journey, including patients and caregivers. What emerged was a framework for the CaLM model that focused on delivering care and building services where there were clear gaps (see Figure 2, page 26). The CaLM framework includes the following key components:

- **Understanding the whole person.** CaLM incorporates all aspects of well-being into a holistic care experience by learning about the psychological, emotional, physical, social, cultural,

practical, and spiritual needs and preferences of patients and their loved ones. CaLM uses this knowledge to support them.

- **Relational, empathic care.** The model provides a single point of contact for care coordination. CaLM provides relational care by nurturing strong, trusting, and consistent relationships between patients, families, and our providers. Empathy is the guiding principle—how providers act, treat patients, and treat one another.
- **Coordination and integration.** The model connects providers to the patient by bridging gaps in data, knowledge, communication, and information and overcoming system fragmentation.
- **A home across the continuum.** Survivorship is a cornerstone of the CaLM model, which is tailored to patients’ cancer journeys. Whether patients have advanced disease, are on a curable trajectory, or are living with cancer as a chronic condition, CaLM is a touchstone of love and support during and after active treatment.
- **Dimensionally accessible care.** Livestrong Cancer Institutes is committed to delivering affordable, high-quality care that is geographically located where patients have reasonable transportation and that delivers the breadth of services needed.

Figure 2. Framework for the CaLM Model



- **Education for shared decision making.** The CaLM model prepares healthcare providers, patients, and families by breaking down clinical terminology to better discuss difficult topics, address gaps in health literacy, and empower patients to make decisions that reflect their preferences and values. CaLM shifts the care away from a traditional, patriarchal healthcare delivery system in which the physician drives care without assessing patient preferences.
- **Personalized and individualized care.** Treatment and care planning are tailored to the unique needs and values of the individual. CaLM respects the preferences of patients and their loved ones, supporting their participation in care in a way that is culturally respectful, valuable, and meaningful.

We recognized that building a successful model of patient-centered cancer care went beyond seeking a stamp of approval from patients and survivors to engaging them to help co-design the model from the inside out. In March 2018 we brought together a diverse group of 29 individuals to form a Patient and Survivor Advisory Board. The advisory board worked closely with our team to determine how to operationalize CaLM, keeping patients’ needs and values as our North Star. (Of note: The Patient and Survivor Advisory Board helped develop a young adult oncology program due to a significant care gap for this patient population in Austin.) Over 18 months, the patients, survivors, and caregivers on the board worked side by side with our leadership team to design each service line. Specifically, the Patient and Advisory Board:

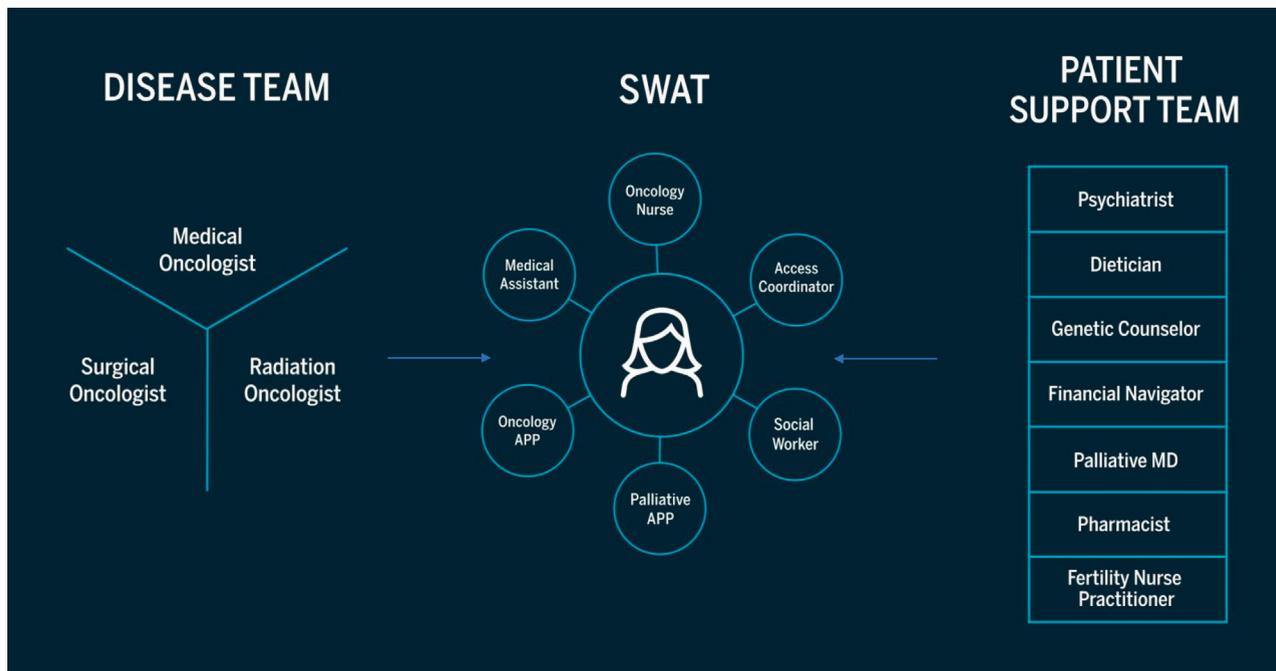
- Provided strategic advice
- Devised criteria for hiring an ideal clinical team
- Participated in job interviews with potential clinical candidates
- Joined in mock operational exercises as we prepared to go live with the model
- Reviewed patient-facing materials
- Advised on resources
- Guided our clinical trial and translational research strategy.

In March 2019, after the clinic opened, the board evolved to include more patients and survivors of different ages, socio-economic status, and geographic locations. Clinical team hires met with the Patient and Survivor Advisory Board to optimize the new working oncology program. It is our vision to anchor the CaLM model in the lived experiences of those affected by cancer, moving away from bringing the “work to the patients” to a place where we “bring the patients to the work” in order to further integrate our patient advisors in the planning and operations of our model.

Implementing an Interdisciplinary Care Team Approach

The CaLM model’s infrastructure is built on a foundation of collaborative, interdisciplinary providers called the patient support team. This team consists of supportive care experts who collaboratively manage patients’ care by assessing and addressing

Figure 3. CaLM Staffing Model



patients’ needs and values. At the heart of the patient support team is the SWAT team, which is composed of an oncology advanced practice provider, palliative advanced practice provider, supportive care and survivorship doctor, oncology social worker, nurse navigator, medical assistant, and community navigator. This team triages patients, manages symptoms, provides education and clinical navigation, and conducts a whole-person assessment to proactively manage the patient’s treatment and care. Medical, surgical, and radiation oncologists comprise the disease team that drives the treatment planning process; they plug in to the SWAT team but, unlike a traditional model of cancer care, they do not need to see the patient at each visit. The CaLM staffing model (Figure 3, above) encourages oncologists to focus on treatment planning and decision making, while reducing patient reliance on them for services outside their scope of practice. This methodology of staffing results in:

1. Payer cost savings due to maximizing oncologists’ scope of practice and increasing patient volume.
2. Patients’ immediate access to subspecialists to manage their specific needs.
3. A single point of contact for patients when coordinating care.
4. Clinical providers work at the top of their license.

After completing patient-reported outcomes (PROs) and intake forms, patients meet with the SWAT team for a whole-person assessment throughout the first several visits. Patients first see a disease-specific advanced practice provider. Depending on patients’ priorities, symptoms, and immediate needs, the palliative advanced practice provider or social worker may meet with patients and their families to share the types of integrated services that CaLM provides (and patients may schedule separate visits later). Patients

may also need to meet with one or more members of the patient support team. During this same initial visit, some domains may be assessed to help the care team get to know the patient and their values (see Figure 4, page 28). Many of these domains are assessed over time as the team builds a strong and trusting relationship with the patient. The clinical team uses the electronic health record (EHR) and/or a document called “Whole Person Assessment” to track these domains. Providers share this information so that all members of the care team have access to the data. Over several months in 2019, the Livestrong Cancer Institutes developed the whole-person assessment process to use components of medical oncology intake forms, psychosocial distress screens and intakes, psychiatric intakes, integrative oncology intakes, and palliative care intakes.

Simultaneous with a patient’s initial visit, his or her case is reviewed during multidisciplinary tumor boards. Once the disease team determines the best treatment options, the oncologist(s) reconnect with the SWAT team and review the treatment options and any patient concerns that may have surfaced in their initial assessment. Afterwards, the disease team meets with the patient to discuss treatment protocols and options, including any clinical trials.

In May 2019 we piloted a weekly interdisciplinary case review for an hour each with the SWAT, disease, and patient support teams to:

- Discuss the patient’s immediate clinical, practical, and psychosocial needs, so that the teams can prioritize services.
- Discuss the patient’s whole-person assessment.
- Develop a comprehensive care plan.
- Coordinate clinical care.

Figure 4. Domains for Assessing the Whole Person

SEXUAL

Fertility
Body image
Sexual needs and issues
Couple communication and needs

CULTURAL

Language
Immigration status
Meaning of pain, illness, death, suffering
Rituals
Health-related preferences based upon culture
Cultural traditions and beliefs

VALUES AND PREFERENCES

Treatment goals
Life goals
Communication preferences

PHYSICAL

Medical history (including family history)
Physical symptoms, chief complaint/issue
Pain analysis (location, cause), discomfort, meaning, history

EMOTIONAL

History of grief, loss, and illness
Coping and strengths
Stress relief
Disease understanding and prognostic awareness
Demographics: race, ethnicity, gender identity, sexual orientation, age, marital status, kids, employment, living situation, religion, spirituality, language, health literacy, immigration status, socioeconomic status, family structure, etc.
Personal trauma
Sources of support
Communication preferences
Cultural/ethnic, spiritual, and familial needs

SOCIAL AND PRACTICAL

Social history and development life history
Social determinants of health
Financial issues
Cancer, jobs, education
Social community and support system; family system and impact on family (including children in family)
Education level
Sleep
Exercise
Spiritual or meaning making practices

Each expert weighs in on the patient’s major challenges to ensure coordinated and streamlined care. This case review process is critical in helping the team map a complete picture of the whole person and his or her family and life context. By asking, “What’s important to you, today?” and building trusting relationships with patients and caregivers, we know our patients and the challenges they face outside the clinical setting and keep a pulse on patients’ priorities. Over the patient’s next visits, the SWAT, patient support, and disease teams work with patients to develop a care plan that includes cancer treatment, symptom management, emotional support, nutritional support, and any other components that patients need (see Figure 5, right). Most critical resources and services are delivered internally. CaLM service lines (in-house programs) include:

- Nutritional support
- Palliative care and symptom management
- Psychosocial and emotional support
- Genetic counseling
- Financial counseling
- Care coordination (navigation)
- Fertility preservation.

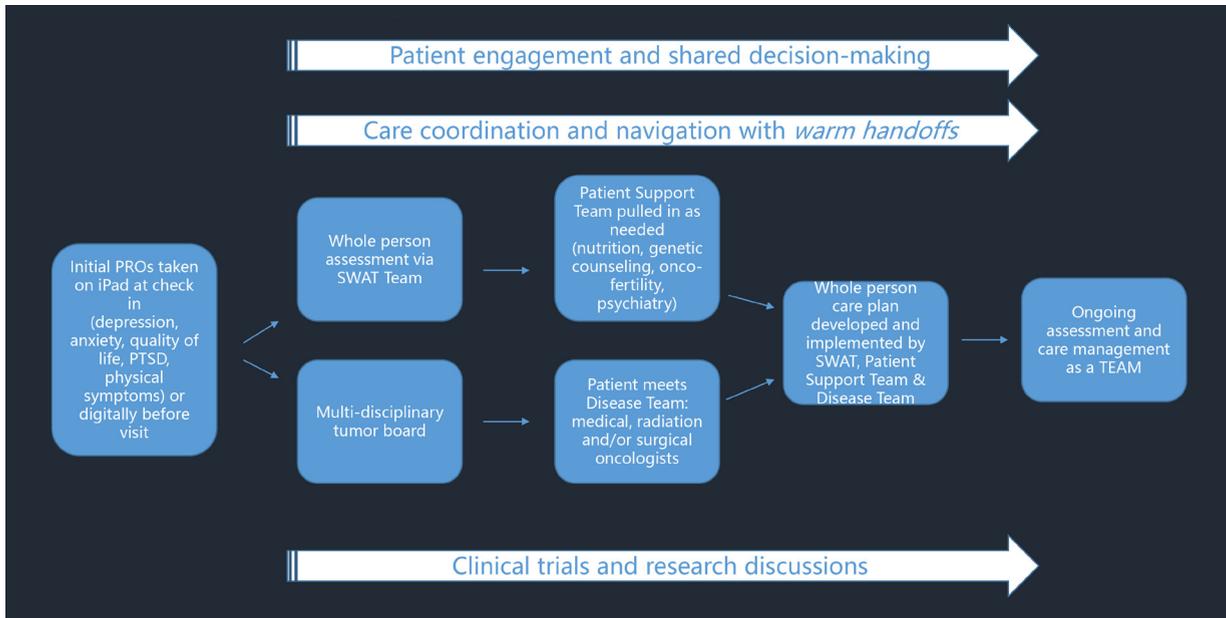
Livestrong Cancer Institutes also make referrals out to the local community for physical therapy (prehabilitation/rehabilitation), spiritual care, career and legal support, wellness/fitness/yoga programming, and integrative oncology (see Table 1, page 30). We plan to launch some of these service lines in-house in the near future.

Effective Teamwork Requires Specific Training

As more cancer programs move toward a team-based approach to care, clinicians can struggle with working functionally in their teams. Cancer care is complex and requires healthcare providers across disciplines to collaborate to learn, assess, problem solve, and deliver coordinated care,⁷ but seasoned clinicians may not have had the interprofessional training to equip them with the skills and tools to collaborate successfully. Our team recognizes that we cannot simply put hired clinicians together and expect them to work as a team. We need to train and teach clinicians how to be most effective in these teams. Accordingly, Livestrong Cancer Institutes is working with Dell Medical School, Center for Health Interprofessional Practice and Education to deliver training that will develop clinician proficiency in the following competencies:

- Work with other clinical experts to maintain mutual respect, understanding, and shared values.
- Use clinical experts’ full scope of knowledge, skills, and abilities to provide care that is safe, timely, efficient, effective, and equitable.
- Communicate with team members to clarify their responsibilities in executing a treatment plan or public health intervention.
- Recognize how each individual contributes uniquely (i.e., experience level, expertise, culture, power, and hierarchy within the team) to effective communication, conflict resolution, and positive interprofessional working relationships.

Figure 5. CaLM Care Pathway



- Engage with the team to constructively manage disagreements regarding the values, roles, goals, and actions that may arise among professionals and with patients, patients’ families, and community members.
- Plan, deliver, and evaluate care by applying relationship-building values and team principles.

Training is delivered through a series of sessions led by a team—including a physician, nurse, social worker, and pharmacist—that can model effective interprofessional practices. The competencies listed above will be used as a benchmark to assess improvement in desired areas.

Measuring What Matters to Patients

Data show that assessing symptom-related, patient-reported outcomes may actually increase cancer patient survival.⁸ The U.S. Food and Drug Administration defines patient-reported outcomes as “any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.”⁹ The goals of our overarching patient-reported outcomes strategy include:

1. Managing patient symptoms and side effects and screening for issues (in real time when possible).
2. Assessing whether treatments and interventions are effective (and creating adherence to interventions).
3. Assessing patient experience with CaLM services and facilitating patient-centered cancer care.
4. Assessing and managing emotional, social, cultural, physical, financial, spiritual, and practical issues and needs of patients and caregivers over time.

5. Providing a common frame for the CaLM interdisciplinary team to use when discussing and/or implementing whole-person care.
6. Engaging patients in their healthcare journey and managing their health.

In 2018 the Livestrong Cancer Institutes implemented a vigorous process (see box on page 31) to select appropriate patient-reported outcomes to test in the CaLM model, utilizing the “capability, comfort, calm”¹⁰ framework of Elizabeth Teisberg, PhD, and Scott Wallace, JD, MBA, of the Dell Medical School, Value Institute for Health and Care. Their research findings identify three outcomes that matter most to patients’ healthcare experience:¹¹

- **Capability.** Frequency or degree to which patients can do what matters to them.
- **Comfort.** Freedom from physical and/or emotional pain and/or suffering.
- **Calm.** Patients’ abilities to live their lives as they pursue care (free from the chaos of the healthcare experience).

In the CaLM model, patients receive five short digital assessments (in English or Spanish) either 24 hours before their appointment via email or SMS, or on an iPad at check-in. These include the Generalized Anxiety Disorder assessment (GAD 2/7) to gauge anxiety, the Patient Health Questionnaire (PHQ 2/9) to measure depression and suicidality, the Functional Assessment of Cancer Therapy (FACT G) to assess quality of life, the MD Anderson Symptom Inventory to assess physical symptoms, and a modified version of the Primary Care Post-Traumatic Stress Disorder

Table 1. CaLM Community Partners

Organization	Program/Service
Wonders & Worries	Counseling and support programs for children with a parent dealing with cancer
Regarding: Cancer	Peer matching for cancer patients and caregivers
CANLAW	Access to free professional legal services for cancer patients and their loved ones
American Cancer Society	Navigation support to local and national resources; cancer information
Cancer Rehab and Integrative Medicine	Acupuncture, oncology massage, physical therapy, lymphedema therapy
Cancer and Careers	Online resources and support for employment issues when coping with cancer
HorseLink	Equine therapy and daylong retreats for patients and loved ones
Flatwater Foundation	Financial coverage and access to one-on-one therapy or counseling with licensed professionals for longer term emotional support for patients or loved ones
Livestrong at the YMCA	Free/low cost exercise and wellness 12-week program for cancer patients and survivors
Yoga 4 Cancer	Free or low-cost group yoga classes geared toward patients and survivors at any phase of treatment or in post-treatment survivorship
Livestrong Fertility	Access to free fertility preservation stimulation medication (women) and discounted services (extraction, freezing) for men and women

Assessment to measure any post-traumatic stress disorder (PTSD) from traumatic life events (e.g., a cancer diagnosis or previous cancer-related experience). Each assessment is conducted at the patient’s first visit and every medical oncology and/or SWAT visit that follows. We track patients’ symptoms, side effects, and emotional issues over time, so that we can address them immediately. Table 2, right, shows the validated patient-related outcome tools in use, the subdomain that each measures, and the cadence of assessment.

Interconnection with Local Cancer Care Delivery System

To deliver high-quality, person-centered cancer care, we need to work in tandem with the local cancer care delivery system. Central Texas has more than 45 non-profits, cancer organizations, and institutions that provide cancer-related services or programs to patients and their families, and numerous other organizations provide access to needed social services for indigent and vulnerable patients. To leverage these existing resources, the Livestrong Cancer Institutes partnered with these organizations and built

referral pathways in our navigation strategy. Our team reaches out on behalf of the patient to community resources to minimize the barriers that patients face when seeking referrals.

Table 1, above, lists some of the organizations with whom we have built robust partnerships and direct referral pathways. The vetting process before initiating memorandums of understanding with each organization includes holding initial discussions, streamlining referral pathways, and making site visits to understand the nuances of their service, ensure alignment with our navigation methodology, and develop ease of access for patients.

Is the CaLM Model Working?

Our team has built a robust evaluation strategy to assess the impact of the CaLM model. In addition to tracking traditional clinical measures, we plan to measure:

- Whether patient goals are defined and met through care coordination, quality of care, and symptom management.
- Patient access to treatment and care.
- Provider burnout rates.
- Patient ease of referral and communication with community partners.

Table 2. Patient-Reported Outcome Measures Used in the CaLM Model

	Domain	Sub-domain	Cadence
Generalized Anxiety Disorder Screen (GAD 2)	Comfort, calm	Anxiety	First visit and every visit
Patient Health Questionnaire (PHQ 2/9)	Comfort	Depression	First visit and every visit
Functional Assessment of Cancer Therapy (FACT-G)	Capability, comfort	Quality of life: physical, social, emotional, and functional well-being	First visit; then every 3-6 months as needed
MD Anderson Symptom Inventory	Comfort, capability	Physical symptoms: pain, fatigue, nausea, disturbed sleep, distress and/or feeling upset, shortness of breath, difficulty remembering, lack of appetite, drowsiness, dry mouth, sadness, vomiting, numbness, and tingling	First visit and every visit
Primary Care Post-Traumatic Stress Disorder Assessment	Comfort	Trauma, post-traumatic stress disorder	First visit; then every 3-6 months as needed

Currently, EHR limitations prohibit us from collecting these data, but we are preparing to switch to a more functional and appropriate EHR built for oncology settings. However, based on early data collected via patient-related outcomes, we are seeing trends that the CaLM model is improving patient quality of life and reducing severity of physical and psychosocial symptoms. Figures 6-7, pages 32-33, show baseline and follow-up anxiety scores for a small population of patients from June to August of 2019. The data in Figure 7 illustrates a decrease of mild-to-moderate and severe anxiety from 41 percent to 28 percent of patients. As our clinic continues to grow in patient volume, we expect the data to continue to trend in the same direction with an increase in patients with no to low anxiety and a decrease in severity of anxiety.

More recent data show that the CaLM Model also improves physical symptoms (Figure 8, page 34). Data are from the MD Anderson Symptom Inventory baseline results (initial visit) and endline results (most recent visit previous to March 1, 2020). Trends show a reduction of moderate and severe pain (a decrease from 40 percent to 33 percent combined); by their most recent visit, nearly two thirds of patients rated their pain as mild. The data also illustrate a decrease in severe fatigue of 11 percent, from 34 percent to 23 percent, and a decrease in moderate and severe symptom interference in mobility by 16 percent.

Two Qualitative Examples of Success

Patient A

A gastrointestinal oncology patient first came to the Livestrong Cancer Institutes at UT Health Austin after receiving treatment

Selecting Our Patient-Reported Outcomes

Our team piloted a PRO baseline research study in the Seton Infusion Center with nearly 150 patients and caregivers. We collected data at two time points and used several measures, including the FACT-G with Palliative Module (to measure quality of life); PROMIS-Cancer Specific Measures (to measure function, anxiety, depression, fatigue, and pain); COST tool (to measure financial toxicity); CAHPS survey (to gather data on the cancer care experience); and the BASC tool (to gather data on the caregiver experience). The overall model for factors impacting quality of life showed that depression and pain significantly decreased quality of life, and for every one unit increase in the COST score, we get one unit increase in quality of life. The CaLM model controls for cancer stage, type, race, and age.

In May 2018, a large cross-functional team of providers, social workers, researchers, nurses, and experts from across the Value Institute, Oncology Department, palliative care, psychiatry, and the cancer community (Livestrong, Seton) gathered to hold a deep-dive discussion about our PRO strategy.

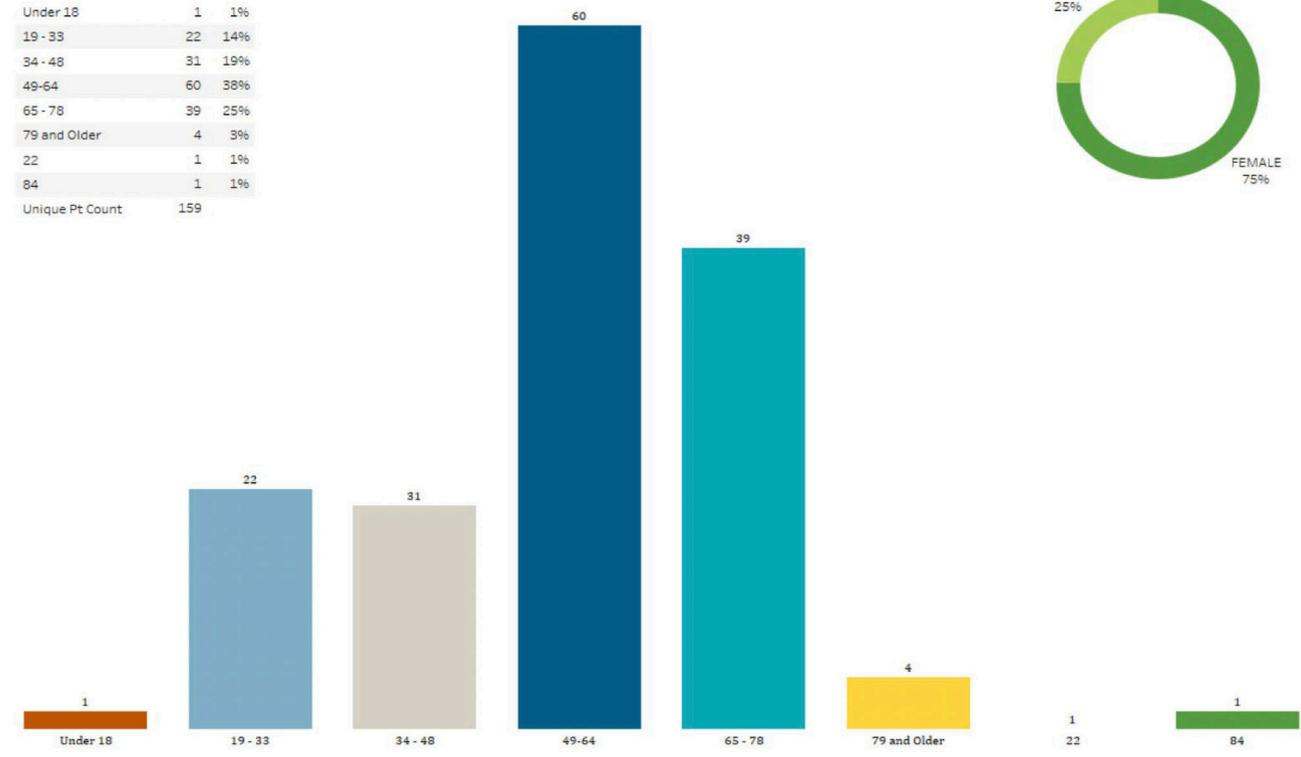
In July 2018, the Cancer Institutes' Patient Advisory Board held a mirroring discussion to provide their input, and the participating patients and caregivers expressed strong approval for the list of PROs and domains, validating and adding to it.

In August 2018, our PhD researcher compared the list of PRO domains to peer-reviewed literature to map it against best practices and identify validated tools for each domain where possible.

Figure 6. CaLM Patient Demographics for GAD Data

Patients by NIH Age Group and Gender

Under 18	1	1%
19 - 33	22	14%
34 - 48	31	19%
49-64	60	38%
65 - 78	39	25%
79 and Older	4	3%
22	1	1%
84	1	1%
Unique Pt Count	159	



NIH age group source
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3825015/>



at another well-known local cancer center. The patient presented stable disease but was not satisfied with treatment for his anxiety and physical symptoms. He had been given referrals for emotional support without direction on how to select a psychosocial provider, which was extremely confusing to him. He self-referred to us after reading about our program on our website. At his first visit, he filled out the patient-related outcome assessments, which demonstrated severe anxiety and depression. As the team reviewed his results and spoke with him about his immediate concerns, it became clear that the primary issues requiring triage were his mental health and palliation of gastrointestinal symptoms. Because his disease was stable and he was on maintenance chemotherapy, the team facilitated a shorter “meet and greet” with his gastrointestinal oncologist and opted for a more robust assessment and treatment with the clinical social worker, oncology psychiatrist, and palliative care advanced practice provider. As a result, the team was able to stabilize the immediate issues that had been causing him high distress. The patient now has regularly scheduled visits with an oncology psychiatrist and the palliative care team, and his psychosocial issues are under control. His colorectal

cancer is periodically co-managed by Livestrong Cancer Institutes at UT Health Austin and MD Anderson Cancer Center.

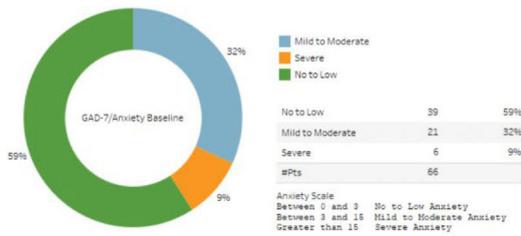
Patient B

An oncology patient initially refused treatment because she preferred alternative treatment options. She had specific nutritional needs and preferences that she wanted honored. After her first visit, the SWAT team better understood the context of her life and her values and preferences. The whole-person assessment identified that her religious beliefs conflicted with the treatment regimen she was offered and her deep-rooted fear and mistrust of the healthcare system. An oncology dietitian worked with the patient to develop a highly personalized nutrition plan that met the patient’s nutritional restrictions and guidelines. Over time, our team continued to provide supportive care without treatment and, while consistently respecting the patient’s values and preferences, the team was able to build trust. The patient soon opted into clinical treatment for her disease.

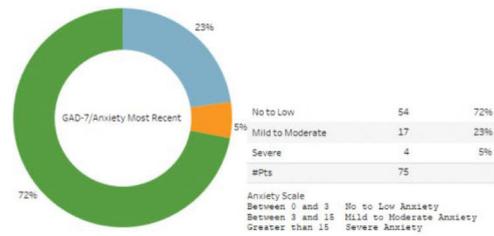
As these patient stories show, the CaLM model is a closely coordinated approach and a change in clinical care culture that results in a connection between providers and patients. Because

Figure 7. Baseline and Endline Anxiety Scores (General Anxiety Disorder Scale)

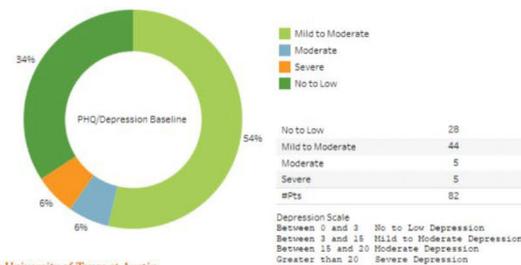
GAD-7/Anxiety Baseline Scores



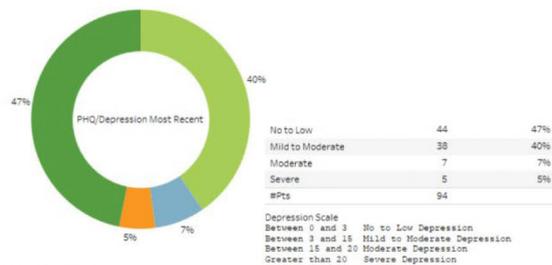
GAD-7/Anxiety Most Recent Scores



PHQ/Depression Baseline Scores



PHQ/Depression Most Recent Scores



referrals outside of the CaLM team are limited, all team members are present for daily huddles and conversations and are kept current as patient treatment and/or care evolves. Clinical treatment alone does not encompass whole-person care. These examples illustrate that to improve patient quality of life, the needs of the mind, body, and spirit must be addressed. Lastly, a relational, empathic approach requires building trust over time in small transactions with patients and caregivers. Because patients see the same empathic providers at every visit, the CaLM model forges therapeutic, trusting relationships between patients and their care team; providers receive honest information to truly meet patients where they are.

Lessons Learned

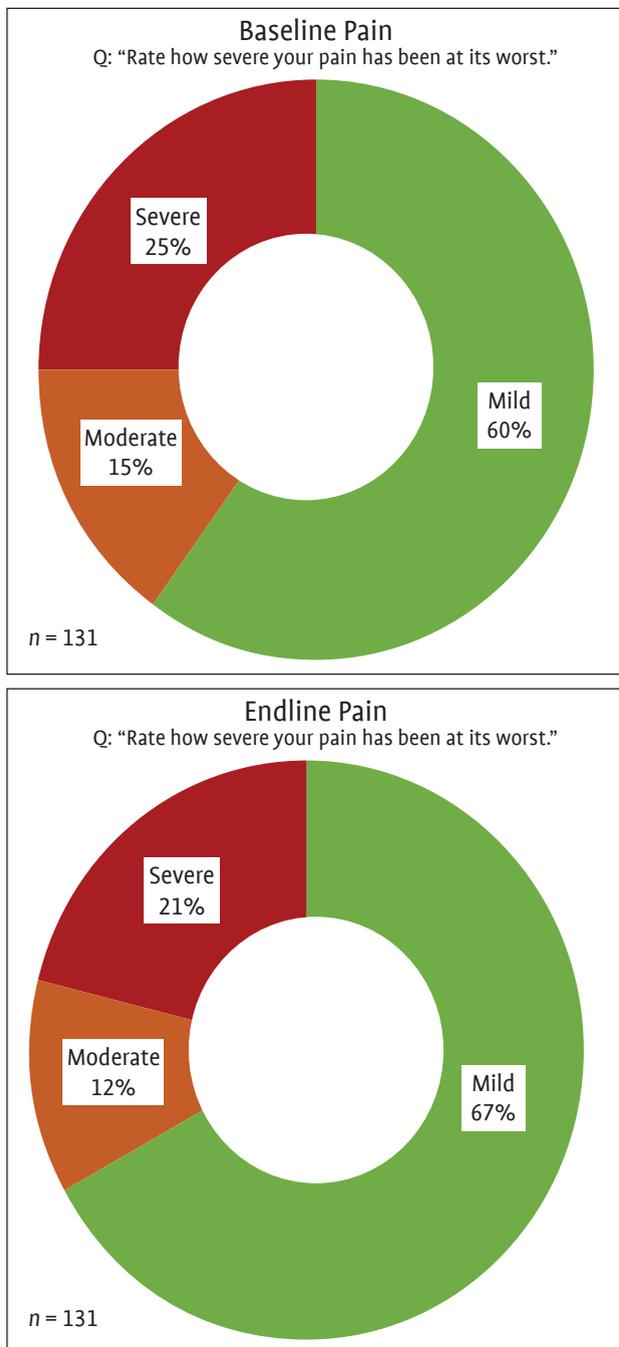
Figure 9, page 35, offers a brief timeline of program development and implementation of the CaLM model. Below are key lessons learned during the program's first year of operation:

- **Teams have baggage.** Although many believe in the power of interdisciplinary care teams, few healthcare professionals are trained in effective teamwork, and even fewer have experience with this approach to care. We opened our clinic expecting providers to have bought in to this idea, without any training or clearly defined roles and responsibilities. We assessed for resilience and adaptability in interviews, but that did not always translate into the start-up environment. Encouraging providers to put the patient first and to have an “all hands-on

deck” approach without training and support will not lead to desired outcomes. Providers bring components of their previous institutions’ culture, even if only subconsciously. To address this, our team is working with the Center for Inter-professional Practice and Education (healthpe.utexas.edu) to train the team in this emerging field.

- **Everyone will tell you “No.”** Change is not easy, especially in healthcare. Just because a team wants to innovate, disrupt, and rethink healthcare does not mean that it understands the high level of detailed work, flexibility, and perseverance that change takes. Building a new clinic from scratch is never easy. Leadership may accuse you of being inefficient; referral partners may think you are naïve; and you may have to defend every decision you make. The care team may even question all of the non-clinical work it takes to effect change, but if you stay the course, listen, and are willing to iterate, it will not happen overnight but you may get there.
- **Patients may not trust you.** Patients—especially patients with cancer—are not always treated well. They may experience poking or prodding without understanding why. They may feel identified as if they are their disease rather than a person. Patients have an expertise that few practicing oncologists have: what daily life is like with cancer. When developing patient advisory boards or other patient engagement efforts, trust, consistency, and respect must be earned. One of the first members of our Patient and Family Advisory Board was hesitant

Figure 8. Results are illustrated for all patients seeking active or survivorship care for cancer at some point between December 2018-February 2020, excluding patients seeking solely a second opinion consult. MD Anderson Symptom Inventory asked patients to rate symptom severity and symptom interference at their worst, within the last 24 hours. Ratings were aggregated as follows for analysis: 0-3: Mild Severity or Interference; 4-6: Moderate Severity or Interference; 7-10: Severe Severity or Interference.



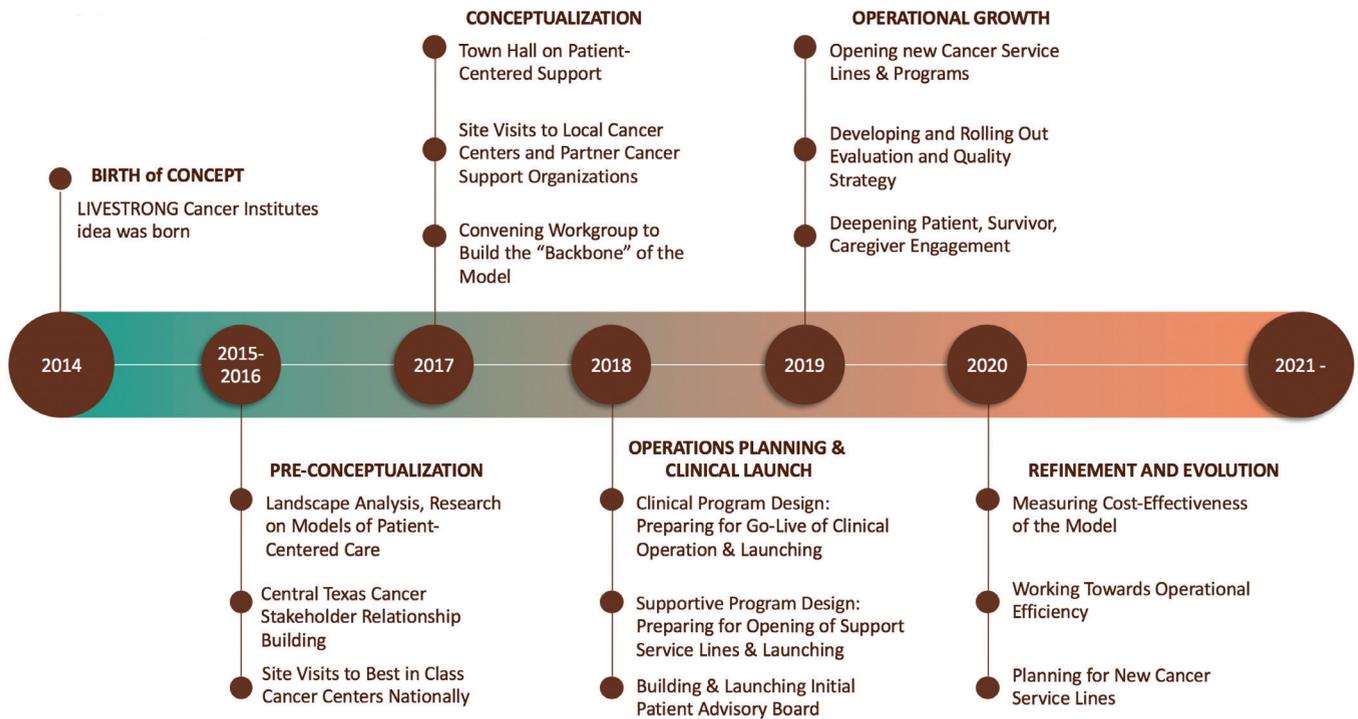
to work with us. He is the father of a post-treatment cancer survivor who was diagnosed at eight months old and told us that he would not be our “yes man.” He recognized that some patient boards may simply rubberstamp ideas intended to serve the healthcare system so that they are “approved” by patients and caregivers. After learning about the CaLM model—our intentions to co-design with patients and family and recognize patients and loved ones’ unique expertise—he finally joined. Over the past year, our team has come to know the father and his family by staying consistent with our messaging, accountable to the board, and respectful of how members want to drive the work. This work takes time and does not always fit into project plans and set timelines, but you have to meet patients where they are, listen to what they are saying (not what you want or expect them to say), and push past those who are reluctant to include patients. Patients participated in mock clinical operations in the hallway after our compliance officer told us that we could not have them in the clinic prior to opening. When our leadership discouraged us from involving survivors in clinic launch preparations, we brought our patient advisors to meetings so that our leadership could speak directly to them. Asking for forgiveness, rather than permission, may be a necessary approach for any innovator.

Vision for the Future

Our hope is to continue to illustrate the efficacy of the CaLM model and gather data (particularly cost-benefit analysis data) that proves that reshaping care to an interdisciplinary, whole-person focus will lower costs for the patient, system, and payer, while improving patient outcomes. Our ultimate goal is to find unique ways to scale and replicate the CaLM model and share it with institutions that want to be forward-facing. We want to share how to bring patients to the work (rather than the work to patients) and how to offer patient-centered care in which patients are at the center of all aspects of care—from design and implementation, to directing and evaluating. Because no program, service, or material is introduced in our clinic without our patient advisors helping to design the effort, we will let Christina have the final word on what we offer.

“I know some things about my future: that it will involve more treatment and that I am likely to die far sooner than I hoped. I know to keep holding on to that small flame of initial confidence because while treatment keeps me stable, medicine will keep advancing. I know my care at the CaLM clinic is going to allow me to enjoy my life outside of cancer. I will get to laugh at my daughter’s stories and share intimate moments with my husband. I know I want to keep using my voice to tell people about my life and my experience. It makes me feel strong, and I hope it can help someone else—be it getting tested themselves or just learning how to better support a friend going through it. Knowledge is power, and I am happy to share mine.” 

Figure 9. CaLM Timeline Roadmap



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