PATIENT-CENTERED CANCER CARE: OPPORTUNITIES FOR INNOVATION

IDEAS TO ADVANCE PCCC FROM ADVOCATES, THOUGHT LEADERS, AND INFLUENCERS

INSPIRING HEALTHCARE STAKEHOLDERS TO CONSIDER HOW THEY MIGHT ENHANCE MODELS OF PCCC WITHIN THEIR OWN INSTITUTIONAL CONTEXT
In the cancer space, no single institution to date has been able to successfully implement a comprehensive model of patient-centered cancer care. While the cancer community knows what patient-centered cancer care means, we have an unprecedented opportunity to determine how to deliver it in a way that results in the patient feeling informed, respected and cared for. This is why in June of 2014, LIVESTRONG Foundation gathered a select and dynamic group of patients, survivors, caregivers, health care providers, academics, researchers, community organizations, business leaders, policymakers and innovators from around the country to discuss how to deliver the essential elements of patient-centered cancer care.

In the United States, nearly 14 million people have had cancer and more than 1.6 million new cases are currently diagnosed each year. By 2022, there will likely be 18 million cancer survivors and by 2030, cancer incidence is projected to rise to 2.3 million.*


"I consider myself a client, not a patient. I'm a customer. I decide who to put on my team and where to get my care from.”

– Beth Foster, survivor

Patient-centered care is “respectful of and responsive to individual patient preferences, needs and values, and ensures that patient values guide all clinical decisions.”

The field of patient-centered care isn’t new; a significant body of knowledge has been amassed over the last 40 years and many models and frameworks from primary, inpatient, and long-term care have been generated, building a strong case for why patient-centered care is the next big thing in healthcare.

In the United States, nearly 14 million people have had cancer and more than 1.6 million new cases are currently diagnosed each year. By 2022, there will likely be 18 million cancer survivors and by 2030, cancer incidence is projected to rise to 2.3 million annually.*

We stand at a critical juncture and we can usher the field of cancer care into a new era of patient-centeredness. Within this brief, we offer trends and guidance about the evolution of patient-centered cancer care from key change makers and thought leaders working in the field. Our hope is that individuals and institutions will share these findings with their colleagues and networks, and use them as a jumping off point to explore new innovations in their practice beginning today.
The Foundation embarked on a journey to identify a list of essential elements of PCCC with the goal of constructing a useful tool to help advance delivery of truly patient-centered cancer care. We started with a list of over 110 elements that were identified from an extensive review of nearly 150 sources from across healthcare, including cancer care. Over several months of research, we bundled elements that were conceptually similar, mapped them onto categories (patient, family, provider, or system focused) and cross checked them against the Institute of Medicine’s (IOM’s) framework for high-quality cancer care. We made sure that the collection covered the big ideas for the national conversation and addressed multiple dimensions of cancer care delivery.

To our knowledge, this collection of elements is the most current and specific list of “to-dos” to make patient-centered cancer care a reality.

The Elements of PCCC are a collection of key building blocks that can be utilized to deliver cancer care across a variety of settings. One way of viewing the 23 elements of PCCC is within 7 overarching themes. These themes collectively comprise the foundations for Patient-Centered Cancer Care. They are the “big” ideas. Elements that lie in areas of overlap have the potential to impact more of the care system when implemented.
12 OF THE 23 ELEMENTS WERE SELECTED AS MOST ESSENTIAL TO DELIVER PATIENT-CENTERED CANCER CARE

“Patient-centered care is not an isolated aim. It’s a unifying one.”
Randall Carter, Senior Vice President, Planetree

Communication, incentives, integrated care, transparency all key to #deliveringpccc @livestrong
http://ow.ly/ydJPa
DELIVERING THE ELEMENTS

“To me a place can say it’s patient-centered, but it doesn’t mean anything if they can’t back it up.”
Dr. Abby Prestin, Lymphoma survivor
Attendees were asked to ideate solutions for how to implement the elements of PCCC.

The following are snapshots of tangible ideas crafted throughout symposium discussions and activities.

**IDEAS FOR IMPLEMENTING THE ELEMENTS OF PCCC**

**ACCESSIBLE, TIMELY, CLEAR, AND EFFECTIVE COMMUNICATION**

**ACTIVATING**

“Humanize” care with a cross-silo patient journey tool that maps all patient experiences through treatment and into post-treatment survivorship. Use the data to create patient personas that can inform providers on how to best communicate with different types of patients and further support provider communication skills with education.

Use technology across multiple platforms (i.e., including mobile) to facilitate secure communication that captures communication in standardized data elements, including speech-to-dictation capability, for integration into the electronic medical records (EMR).

Provide an online patient navigation and information platform with real-time, face-to-face assistance for patients, advocates, and family members including access to all medical records. Partner with industry (e.g., Google) for a cloud-based data service foundation and when accessed via a mobile device, connect the monthly phone bill to payment and reporting.

Create an online, mobile-based social network that connects all members of the care team to the patient and, with the patient’s permission, their family and caregivers. Have an Internet-based platform option available for patients who do not have smartphones.

Create and/or invest in an online, cloud-based, secure application or tool where patients have a unique de-identified ID number and all providers and patients can communicate at no cost to the patient.

---

Watch video

As a cancer patient, I want to feel like a person, not some doctor’s project
#deliveringpccc At the @livestrong June Symposium
Elise Frame @EliseFrame
The needs, preferences, and values of the patient are the foundation of care decisions.

Understanding

Create a multidisciplinary culture of care that normalizes advanced care planning and advocates for a 1:1 navigator/mentor/peer-support for the patient.

Create a mobile patient-reported outcomes application that uses ecological momentary assessment to capture patient generated data outside of clinical encounters. The app also can be used to send personalized messages to the patient from their care team.

Implement triage staff members, affording them the ability to work with patients prior, during, and after treatment in a tiered model of support. Fund longitudinal research to demonstrate the value and cost-effectiveness of the approach, and leverage the results to change payer policies about coverage for these kinds of services.

Implement one to three questions asked at the beginning of each medical visit to assess the patient’s current values. Use a “primary facilitator” to gather this information ahead of the clinical encounter and to provide a summary of the clinical encounter via a secure patient portal.

Understanding

Understandings

Ideas for Implementing the Elements of PCCC

Provide access to skilled psychosocial providers (social workers, psychologists, psychiatrists) as part of a “village-style” medical home wherein the providers are available for scheduled and on-demand appointments, and their services are billable encounters.

Make family, caregiver, and child support part of the care plan. Psychosocial support, including child life specialists, is available to all and time to utilize those services is protected. A team wiki is used to facilitate problem solving and communication across all members of the care team.

Ellen Beckjord @ebeckjord

@Fayruz: #deliveringpccc is never forgetting the human moment, the human element of care.
COORDINATING

Identify the key players and do a demographic study of their experiences and resource needs.

Create a secure, online record that all parties can view and comment upon.

Have a full-time employee whose position is dedicated to coordinating care for the team. Part of this could include organizing regular (e.g., bimonthly) lunch meetings that are dedicated to coordination of care.

Have an integrated, multidisciplinary care team available to the patient throughout the cancer care continuum. Support the care team with an electronic infrastructure that provides secure information sharing and communication.

Use medical science liaisons to partner with patients (“customers”) to promote understanding of available clinical trials. Integrate existing web-based resources on best practices and new evidence into the medical infrastructure used by the patient team.

Create a secure, regional “open forum” that allows patients to express concerns outside the context of their specific relationships with their healthcare team, and incentivize patients and providers to participate. The forum may build on what some health care payers already provide, and discussions should be gauged against national standards of care.

“Communication begins with listening. A part of what we’re trying to change is to empower these conversations for the patient’s preference.”

Dr. Brad Hesse, Chief Health Communications and Informatics Research Branch, NCI
Ideas for implementing the elements of PCCC

Timely and No-Cost Access to Up-to-Date Medical Information

Communicating

Build a system that allows for free-flow of data through electronic health records for all patients. Incorporate a new role – focused on research and the adoption of new and innovative medical procedures – that facilitates collaborations within the care team and with other health care facilities.

A Technology Enabled Learning Health-Care System

Communicating

Provide every patient with a sensor-enabled “SmartWatch” that transmits user-reported and passively-sensed data securely to the electronic medical record and patient-facing personal health record. Solicit feedback from users early and often. Incentivize innovation on the system side.

Provide all patients with wearable devices like a SmartWatch to monitor biometrics and allow patients to respond to push notifications at intervals between clinical encounters. Track whether and how these devices improve the efficiency of care and lower costs by enabling self-management.

Create a patient reported outcomes “start up” (accelerator, incubator, competition) and work to create an entire ecosystem of fast-moving companies that address various challenges in collecting patient reported outcomes. Hire tech-savvy staff who can facilitate integration, training, and HIPAA navigation.

Survivorship Care Planning

Communicating

Provide a portable, secure, internet-based survivorship care plan available on multiple platforms. Use open-source software and design for accessibility even among individuals with low health information technology literacy.

"Medicine killed my cancer but people saved my life.”
Patti Rogers @rallyhood on the importance of community in cancer care. #deliveringPCCC
IDEAS FOR IMPLEMENTING THE ELEMENTS OF PCCC

EMPOWERING

Crowdsourcing strategies and solutions for common communication problems and instilling appropriate cultural competencies and trainings for providers.

Implement education and training for medical students and resident physicians led by faculty and community practice physicians led by communication experts who can provide guidance on how to deliver “bad news.” Have the training available in an online format. Use an integrated information technology system to record the information delivered and compare current decisions with prior decisions.

A POSITIVE THERAPEUTIC ALLIANCE BETWEEN PATIENTS, THEIR FAMILY, THEIR CAREGIVERS AND HEALTHCARE TEAM

Advocate for more members on the care team at each cancer center, such as advanced practice providers, social workers, counselors, and integrative medicine practitioners. Start with listening to patients and families to establish a dialogue (held both in-person and technology-mediated) to promote successful long-term relationships. Work to build an ecosystem instead of a top-down structure, and use market mechanisms to drive down costs and improve quality.

Key ideas emerging about #deliveringpccc:
- Teamwork.
- Creativity.
- Dedication.
- Courage.

heather wajer @heatherwajer
Participants were given a press release about a fictional city called Copernicus, Texas, dated June 13, 2017. Copernicus had recently been granted $75 million to build a new model of cancer care. Participants were placed in “task forces” and were given the challenge to work together and articulate a model of patient-centered cancer care that needed to be fully functional by 2020.

In a surprise twist, groups agreed to join forces and collaborate as larger entities. This is group 1’s model.

Key resources
- Thoughtfully designed family/patient facilities
- Well-trained PCCC staff
- HIPAA-compliant patient portal, including the Patient Page

Integration
- Board of Directors represent providers, policy stakeholders, local business and patients
- Partnerships with providers to bridge to our programs

Strategies
- Create a community cancer wellness center in cooperation with existing hospitals
- Patients write their own mission statement and goals; updated monthly

Delivery Tactics
- A portal shares the patient’s goals (with their permission), to help the care team coordinate care
- Partner with US Postal Service to facilitate home visits

Components
- Total Care Coach (TCC)
- Emotional and psycho-social support for the patient and their family and caregivers
- Choice based system for patients

Key partners
- Local providers of the services we hope to offer
- Existing hospitals
- Patients, survivors, and community representatives

Assumptions
- Value-based service instead of fee for service
- Employees trained to provide better social support for patients and families
- Better health information integration

“Conceived Models of PCCC

“The Living Room”
A scalable model for personalized cancer care based on human-centered, choice-driven, technology supported, compassionate care delivery.

The patient “living room” is a virtual space where information and connection can occur between all components of care seamlessly and securely.

Outcomes
- Patient and family satisfaction
- Impact of wellness practices on patient quality of life
- Overall community health

Barriers
- Current culture of physician autonomy
- Educating patients
- A sustainable model of funding to ensure long-term success

“We’re on the threshold of change. We need to jump in with our whole body, not just both feet.”
Tom Kean, C-Change, Executive Director
"The Health Hub"

The care model designed to deliver top-quality care to address physical, emotional, and practical needs.

A patient-centered care system that leverages information technology to meet community member needs across a network of community embedded centers.

Strategies
- A lifestyle coach is THE single point of contact for every patient
- Community assessments ensure services provided are well-matched to community needs

Components
- A learning system that leverages data capturing patient reported outcomes (PROs)
- Preventive care to promote self-management

Key partners
- Community residents
- Integrative healers
- Payers/insurance companies
- Patients and family members

Key resources
- PCCC training for new employees
- A well-trained, robust navigator and peer-support workforce
- Comprehensive care planning occurs for every patient

Delivery Tactics
- A patient portal documents patient needs, values, and preferences
- Identify roles each stakeholder plays within the individual health model

Barriers
- Changing health care culture to be more humanized
- Positive community culture, integration
- Sustainability
- Political support

Assumptions
- Staff are from our medical school
- There is an integrated informatics infrastructure
- Integrative treatments and navigator services are covered by insurance

Integration
- Community organizations make ongoing assessments
- Shared goals with transparent measurement across all relevant stakeholder groups.

Outcomes
- CDC and Prevention Healthy People metrics
- Cost-effectiveness
- Patient satisfaction
- Continuous 360° assessment for providers & staff

The elephant in the room:
“The way we pay for cancer care doesn’t incentivize the type of care patients want”
@sfuldnasso deliveringPCCC heatherwajer @heatherwajer

This is group 2’s model.
SUMMARY

Call to action
Meeting the challenge of delivering high-quality, patient-centered cancer care to every patient every time is ambitious, and it will take time to achieve this goal. The ideas generated at this Symposium point to high-priority elements of patient-centered cancer care and also offer innovative ideas to implement those elements so that cancer care settings can take immediate action toward being more patient centered.

We call upon the collective cancer community—providers, patients, survivors, caregivers, policymakers, researchers, academics, media, and the business community to:

1.) Share this brief with your colleagues and networks to reinforce the importance of the concept of PCCC.
2.) Explore how you might implement some of the elements and ideas presented in this brief in your own care settings.
3.) Connect with LIVESTRONG in the weeks and months ahead to share your ongoing efforts in delivering PCCC.

About LIVESTRONG Foundation
The LIVESTRONG Foundation fights to improve the lives of people affected by cancer now. Created in 1997, the Foundation is known for providing free cancer support services and advocating for policies that improve access to care and quality of life. Known for its powerful brand—LIVESTRONG—the Foundation has become a symbol of hope and inspiration around the world. Since its inception, the Foundation has served 2.5 million people affected by the disease and raised more than $500 million to support cancer survivors.

One of America’s top non-profit organizations, the Foundation has been recognized by industry leaders including Charity Navigator, the National Health Council and the Better Business Bureau for its excellent governance, high standards and transparency.

For more information, visit LIVESTRONG.org.

Acknowledgements
LIVESTRONG Foundation would like to acknowledge Dr. Ellen Beckjord for leading analysis of the PCCC Symposium results and contributing to creation of the content for this brief.

We would like to express our gratitude to the healthcare providers and other experts who participated in the Symposium as speakers and shared their expertise. We want to thank the experts who served as advisors to the Symposium planning process. And finally, we want to say a special thank you to the amazing patients, survivors, and caregivers who shared their stories during the Symposium, especially:

Jen Garza, Iram Leon, and Patti Rogers, because you are the reason why we do what we do.

participants:

FOR ANY ADDITIONAL QUESTIONS ABOUT THE PCCC SYMPOSIUM OR LIVESTRONG’S WORK IN PATIENT-CENTERED CANCER CARE, PLEASE EMAIL: PCCC@LIVESTRONG.ORG.

What if we could build a system deliveringpccc with all the innovations we can possibly imagine?
http://lustr.ng/1po6gQ1