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.

This PCCC Symposium launched a platform for thought leaders in the field to share best practices and strategies for delivery of patient-centered cancer care.

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 cases 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

23 PCCC ELEMENTS

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
IDEAS FOR IMPLEMENTING THE ELEMENTS OF PCCC

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.

ARCHITECTURE OR A BUILT ENVIRONMENT THAT IS DESIGNED TO PROMOTE A PATIENT-CENTERED EXPERIENCE

UNDERSTANDING

Shift the focus from a health care solution to a community/regional/national health solution, one that encompasses education, safety, and cultural awareness. Instead of building environments dictated by budgets, combine resources with other community groups and hear directly from patients about how building should take place.

Emotional and psychosocial support for the patient, their family and caregivers

OPERATING

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.

@Fayruz: #deliveringpccc is never forgetting the human moment, the human element of care. 
Ellen Beckjord @ebeckjord
Ideas for implementing the elements of PCCC

“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

Coordinated, integrated care across multiple disciplines

**Coordinating**

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.

**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.

Cancer care which incorporates best practices and new evidence as they are generated
IDEAS FOR IMPLEMENTING THE ELEMENTS OF PCCC

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.

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.

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.

"Medicine killed my cancer but people saved my life.”
Patti Rogers @rallyhood on the importance of community in cancer care. #deliveringPCCC
EMPOWERING

Crowdsource strategies and solutions for common communication problems and instill 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.

EMPOWERING

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.
## "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.

### 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

### 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

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

### 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

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

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

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"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

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**CONCEPTUALIZED MODELS OF PCCC**

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.
"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.

Integration

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

Key resources

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

Strategies

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

Outcomes

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

Key partners

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

Assumptions

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

Key partners

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

Barriers

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

Components

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

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Delivery Tactics

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

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"The elephant in the room: "The way we pay for cancer care doesn’t incentivize the type of care patients want" @suldnasso #deliveringPCCC heather wajar @heatherwajar
Participants:
Mary Lou Adams, Candice Aaron, Kim Amtmann-Buettner, Joe Aragona, Clay Battin, Elizabeth Colvin, Meredith Cooper, Susan Cox, Simon Davies, Ana DeFrates, Art Dilly, Erin Donovan, Chris Earthman, Douglas Feil, James Finck, Declan Fleming, Beth Foster, Lewis Foxhall, Dominick Frosch, Shelley Fuld Nasso, Matthew Gardner, Jeff Garvey, Jen Garza, Amber Gillespie, Boone Goodgame, Raymond Greenberg, Gloria Guzman, Tracey Haas, Christopher Hamilton, Brandon Hayes-Lattin, Clarke Heidrick, Bradford Hesse, Tere Holmes, Christine Hornbeek, Russell Hoverman, Sarah Hudson Scholle, Clay Johnston, Barbara Jones, Maninder Kahlon, Tatyana Kanzaveli, Tom Kean, Jessie Violet Larson, Kathy LaTour, Geraldine Lee, Iram Leon, Brad Love, Maria Merek, Sabrina Mikan, Sandy Miller, Jeff Mulhausen, Craig Nichols, Paul Noble-Campbell, Carole O'Toole, Joe Payne, Natalie Richardson, Patti Rogers, Hillary Saltzman, Robert Sartin, Michael Schwartz, Ivana Sehovic, Eugene Sepulveda, Amy Shaw Thomas, Aubree Shay, Kenneth Shine, Will Swetnam, Andrea Taurins, Maksim Tsvetovat, Dale Vidal, Deborah Vollmer Dahlke, Armin Weinberg, Jamilla Williams, Melanie Williams, David Wright, Melissa Young, Patricia Young Brown

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

What if we could build a system that was based on all the innovations we can possibly imagine? #deliveringpccc

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.

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