

# 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



Patient-centered care is on the forefront of the national dialogue about healthcare. The initiation of the Affordable Care Act and an explosion of interest in new models of payment reform to control costs and improve outcomes are indicators that the healthcare landscape is rapidly shifting in the US. Patient-centered care is the next paradigm of healthcare delivery, and it has the power and potential to shift systems and change lives.

"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



## IDENTIFYING AND DELIVERING THE ESSENTIAL ELEMENTS OF PATIENT-CENTERED CANCER CARE (PCCC)



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.\*

"Doctors typically treat disease. Patients experience illness. They are different." Dr. David Wright 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, LIVE**STRONG** 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. 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.

\*IOM (Institute of Medicine). (2013). Delivering high-quality cancer care: Charting a new course for a system in crisis.

Washington, DC: The National Academies Press.

# 7 PCCC BUILDING BLOCKS

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.

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.

#### support nutrition, self-management

 Access to complimentary and alternative medicine
 Access to palliative care
 Support to establish and/or maintain healthy sleep both at home and in the inpatient setting

Ensuring care systems support the entire patient

journey: preventative, co-morbid and palliative care.

•Emotional and psychosocial support for the patient, their

•Supportive care, including preventive care (e.g., care to

OPERATING

Combining all elements to address the patient's values & changing priorities.

#### ACTIVATING

Accessible and effective communication between all parties involved in patient care

#### **EMPOWERING** PATIENTS

Equipping patients and families to engage effectively in the ways that they want.

•Providers who identify and communicate realistic goals to the patient and their family and caregivers

•Education and support to empower the patient's preferred level of participation in informed decision making

•A positive therapeutic alliance between patients, their family, their caregivers, and the health care team

-Access to comparative information about the costs of care before care is provided

•Reasonable wait times before appointments begin and for scheduling future appointments

#### **COORDINATING** & INTEGRATING CARE Synchronizing all parties involved in patient care

through provision of care and systems for care evolution.

•Cancer care which incorporates best practices and new evidence as they are generated

-Care includes multiple disciplines in and outside oncology -Access to genetic testing and counseling

Education, support, and training for all staff to support the implementation of PCCC

•Continuous quality improvement, performance measurement, and integration of new standards

#### COMMUNICATING

Providing systems to ensure all parties involved in patient care are connected and have the right information available.

-A technology-enabled learning health care system that uses data to capture PROs to support the provision of care, both during and between clinical encounters

-Providers, patients, and individuals the patient grants permission to have timely and no-cost access to up-to-date medical information (including access to the patient's medical record)

-Survivorship Care Planning, including provision of treatment summaries, and psychosocial care plan

#### UNDERSTANDING THE WHOLE PERSON Incorporating all aspects of well-being into a holistic

care experience: including the psychological, emotional physical, social, and spiritual.

-The needs, preferences, and values of the patient – including sociocultural, socioeconomic, and spiritual – are continually assessed and serve as the foundation of care decisions

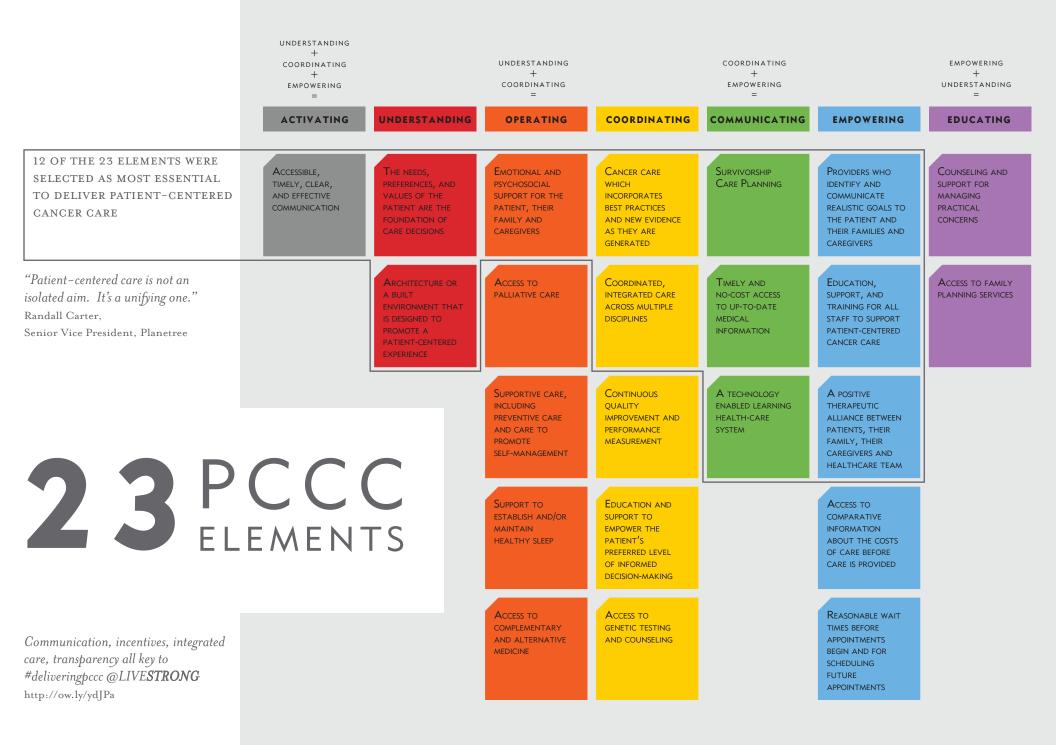
Architecture or a built environment that is designed to promote a patient-centered experience

#### **EDUCATING**

Preparing health care providers, patients and families to dialogue by providing an understanding of all aspects of their cancer journey.

-Counseling and support for managing practical concerns related to cancer such as access to transportation; financial needs; insurance; child care; and advanced directives

 Access to family planning services, such as fertility preservation, reproductive assistance, and adoption support

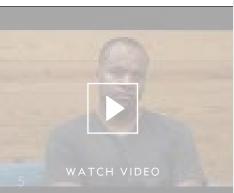


TWO SURVEYS WERE CONDUCTED

Accessible, timely, clear, and

effective communication

DURING THE SYMPOSIUM - THE FIRST FOCUSED ON HOW CHALLENGING THE ELEMENTS ARE TO IMPLEMENT IN A CARE SETTING, AND THE SECOND ON WHICH ELEMENTS ARE MOST ESSENTIAL TO IMPLEMENT IN A MODEL OF PCCC.





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**4**N

Survivorship Care Planning

Counseling and support for

managing practical concerns

19 Access to genetic testing and

13

How essential to a model of patient-centered cancer care

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very essential

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and easier

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"To me a place can say it's

patient-centered, but it doesn't mean

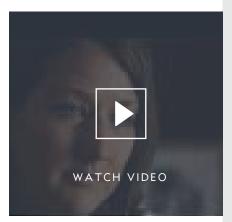
Dr. Abby Prestin, Lymphoma survivor

anything if they can't back it up."

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



As a cancer patient, I want to feel like a person, not some doctor's project #deliveringpccc At the @LIVE**STRONG** June Symposium Elise Frame @EliseFrame ACCESSIBLE, TIMELY, CLEAR, AND EFFECTIVE COMMUNICATION

## ACTIVATING

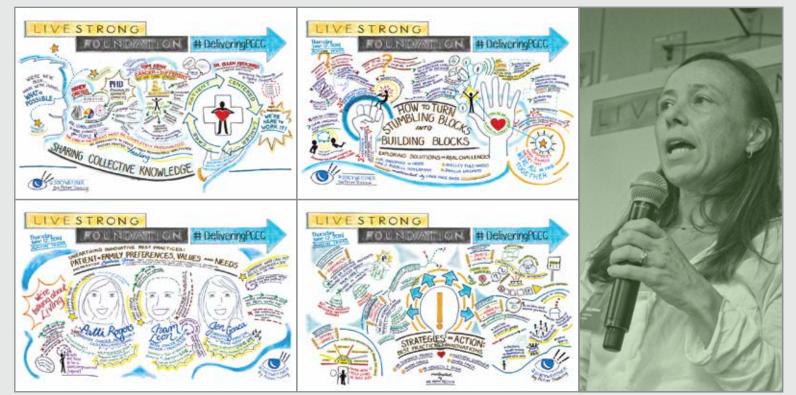
"Humanize" care with a cross-silo patient journey tool that maps all patient experiences through treatment and into post-treatment survivorship. Use the data to create patient personas that can inform providers on how to best communicate with different types of patients and further support provider communication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





## IDEAS FOR IMPLEMENTING THE ELEMENTS OF PCCC

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

### 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 UND

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

THE NEEDS,

PREFERENCES, AND

VALUES OF THE

PATIENT ARE THE FOUNDATION OF

## 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.



## 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

#### CANCER CARE WHICH INCORPORATES BEST PRACTICES AND NEW EVIDENCE AS THEY ARE GENERATED

COORDINATED,

DISCIPLINES

INTEGRATED CARE

ACROSS MULTIPLE

### 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.



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.

## IDEAS FOR IMPLEMENTING THE ELEMENTS OF PCCC

TIMELY AND NO-COST ACCESS TO UP-TO-DATE MEDICAL INFORMATION

**HEALTH-CARE** 

SYSTEM

### 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.

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

A TECHNOLOGY ENABLED LEARNING Provide every patient with a sensor-e

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.



PROVIDERS WHO IDENTIFY AND COMMUNICATE REALISTIC GOALS TO THE PATIENT AND THEIR FAMILIES AND CAREGIVERS

A POSITIVE

THERAPEUTIC

ALLIANCE BETWEEN

PATIENTS, THEIR

CAREGIVERS AND

HEALTHCARE TEAM

FAMILY, THEIR

### 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.

## IDEAS FOR IMPLEMENTING THE ELEMENTS OF PCCC

Key ideas emerging about #deliveringpccc: Teamwork. Creativity. Dedication. Courage. heather wajer @heatherwajer

### 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.

### 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

#### Outcomes

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



#### Components

•Total Care Coach (TCC) •Emotional and psychosocial support for the patient and their family and caregivers

•Choice based system for patients

#### 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

### 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



# 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.

## **Key resources •**Thoughtfully designed

Finoughtuny 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

## "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

#### THIS IS GROUP 2'S MODEL.

CONCEPTUALIZED

MODELS OF PCCC

#### Key resources

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

#### Integration

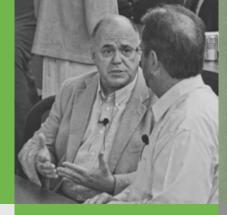
- •Community organizations make ongoing assessments
- •Shared goals with transparent measurement across all relevant stakeholder groups.

#### **Delivery Tactics**

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

#### Outcomes

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



#### Components

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

#### Barriers

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



## 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



*The elephant in the room:* 

@sfuldnasso #deliveringPCCC

heather wajer @heatherwajer

"The way we pay for cancer care doesn't

incentivize the type of care patients want"

FOR ANY ADDITIONAL QUESTIONS ABOUT THE PCCC SYMPOSIUM OR LIVE**STRONG'S** WORK IN PATIENT-CENTERED CANCER CARE, PLEASE EMAIL:

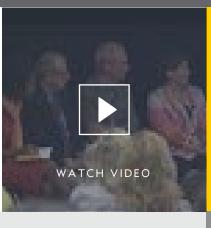
PCCC@LIVE**STRONG.**ORG.

What if we could build a system #deliveringpccc with all the innovations we can possibly imagine? http://lvstr.ng/1po6gQI

#### 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:



SUMMARY

#### Participants:

Mary Lou Adams, Candice Aaron, Kim Amtmann-Buettner, Joe Aragona, Clay Battin, Ellen Beckjord, Fayruz Benyousef, Randall Carter, 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, Hilary 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

#### Acknowledgements

LIVE**STRONG** 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. 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 LIVE **STRONG** in the weeks and months ahead to share your ongoing efforts in delivering PCCC.

#### About LIVESTRONG Foundation

The LIVE**STRONG** 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 – LIVE**STRONG** – 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 LIVE STRONG.org.