

# 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, 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.

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.



UNDERSTANDING  
+  
COORDINATING  
+  
EMPOWERING  
=

UNDERSTANDING  
+  
COORDINATING  
=

COORDINATING  
+  
EMPOWERING  
=

EMPOWERING  
+  
UNDERSTANDING  
=

**ACTIVATING**

**UNDERSTANDING**

**OPERATING**

**COORDINATING**

**COMMUNICATING**

**EMPOWERING**

**EDUCATING**

12 OF THE 23 ELEMENTS WERE  
SELECTED AS MOST ESSENTIAL  
TO DELIVER PATIENT-CENTERED  
CANCER CARE

ACCESSIBLE,  
TIMELY, CLEAR,  
AND EFFECTIVE  
COMMUNICATION

THE NEEDS,  
PREFERENCES, AND  
VALUES OF THE  
PATIENT ARE THE  
FOUNDATION OF  
CARE DECISIONS

EMOTIONAL AND  
PSYCHOSOCIAL  
SUPPORT FOR THE  
PATIENT, THEIR  
FAMILY AND  
CAREGIVERS

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

SURVIVORSHIP  
CARE PLANNING

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

COUNSELING AND  
SUPPORT FOR  
MANAGING  
PRACTICAL  
CONCERNS

*“Patient-centered care is not an  
isolated aim. It’s a unifying one.”*

Randall Carter,  
Senior Vice President, Planeteer

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

ACCESS TO  
PALLIATIVE CARE

COORDINATED,  
INTEGRATED CARE  
ACROSS MULTIPLE  
DISCIPLINES

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

EDUCATION,  
SUPPORT, AND  
TRAINING FOR ALL  
STAFF TO SUPPORT  
PATIENT-CENTERED  
CANCER CARE

ACCESS TO FAMILY  
PLANNING SERVICES

SUPPORTIVE CARE,  
INCLUDING  
PREVENTIVE CARE  
AND CARE TO  
PROMOTE  
SELF-MANAGEMENT

CONTINUOUS  
QUALITY  
IMPROVEMENT AND  
PERFORMANCE  
MEASUREMENT

A TECHNOLOGY  
ENABLED LEARNING  
HEALTH-CARE  
SYSTEM

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

# 23 PCCC ELEMENTS

SUPPORT TO  
ESTABLISH AND/OR  
MAINTAIN  
HEALTHY SLEEP

EDUCATION AND  
SUPPORT TO  
EMPOWER THE  
PATIENT’S  
PREFERRED LEVEL  
OF INFORMED  
DECISION-MAKING

ACCESS TO  
COMPARATIVE  
INFORMATION  
ABOUT THE COSTS  
OF CARE BEFORE  
CARE IS PROVIDED

ACCESS TO  
COMPLEMENTARY  
AND ALTERNATIVE  
MEDICINE

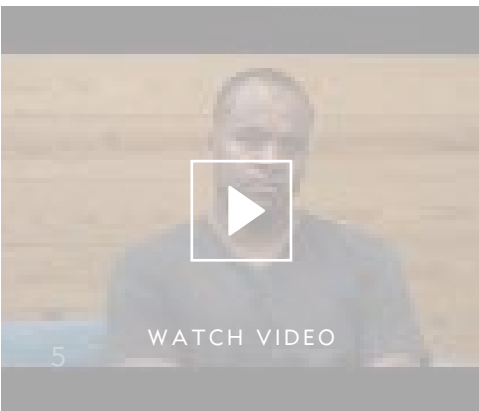
ACCESS TO  
GENETIC TESTING  
AND COUNSELING

REASONABLE WAIT  
TIMES BEFORE  
APPOINTMENTS  
BEGIN AND FOR  
SCHEDULING  
FUTURE  
APPOINTMENTS

*Communication, incentives, integrated  
care, transparency all key to  
#deliveringpccc @livestrong*  
<http://ow.ly/ydJPa>



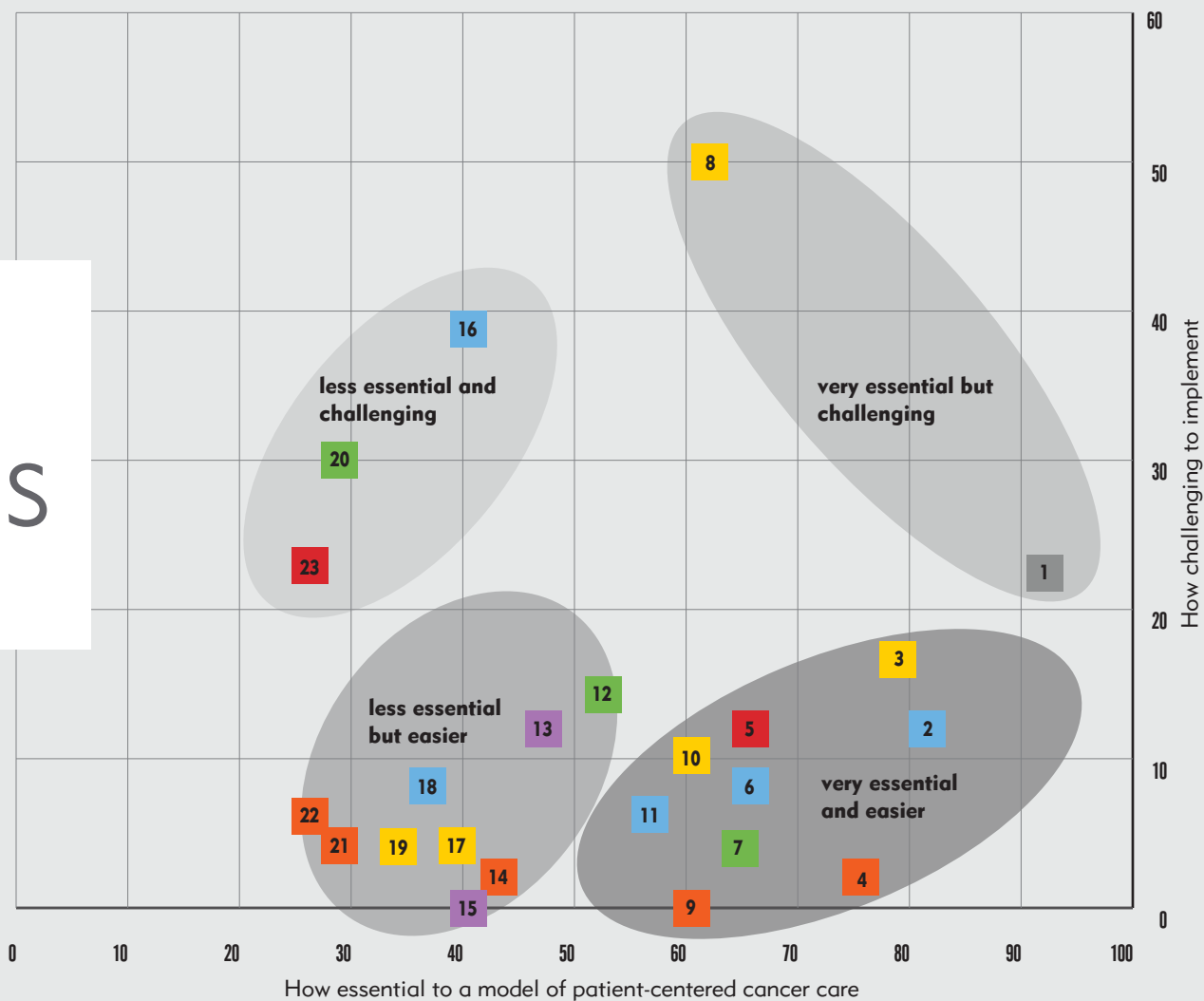
TWO SURVEYS WERE CONDUCTED DURING THE SYMPOSIUM – THE FIRST FOCUSED ON HOW CHALLENGING THE ELEMENTS ARE TO IMPLEMENT IN A CARE SETTING, AND THE SECOND ON WHICH ELEMENTS ARE MOST ESSENTIAL TO IMPLEMENT IN A MODEL OF PCCC.



- 1** Accessible, timely, clear, and effective communication
- 2** Providers who identify and communicate realistic goals to the patient and their family
- 3** Cancer care which incorporates best practices and new evidence as they are generated
- 4** Emotional and psychosocial support for the patient and their family and caregivers
- 5** The needs, preferences, and values of the patient are the foundation of care decisions
- 6** Education, support, and training for all staff to support patient-centered cancer care
- 7** Survivorship Care Planning
- 8** Coordinated, integrated care across multiple disciplines
- 9** Access to palliative care
- 10** Continuous quality improvement and performance measurement
- 11** A positive therapeutic alliance between patients, their family, their caregivers, and the health care team
- 12** Timely and no-cost access to up-to-date medical information
- 13** Counseling and support for managing practical concerns
- 14** Supportive care, including preventive care and care to promote self-management
- 15** Access to family planning services
- 16** Access to comparative information about the costs of care before care is provided
- 17** Education and support to empower the patient's preferred level of participation in informed decision making
- 18** Reasonable wait times before appointments begin and to secure future appointments
- 19** Access to genetic testing and counseling
- 20** A technology-enabled learning health-care system
- 21** Support to establish and/or maintain healthy sleep
- 22** Access to complementary and alternative medicine
- 23** Architecture or a built environment that is designed to promote a patient-centered experience

# 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

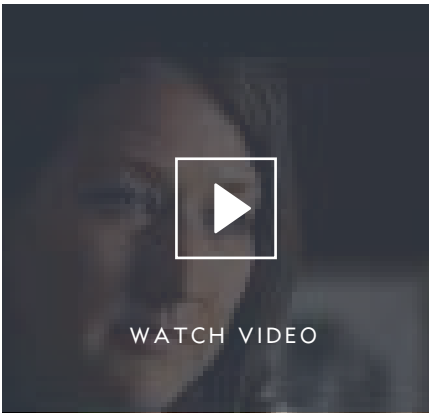
“Humanize” care with a cross-silo patient journey tool that maps all patient experiences through treatment and into post-treatment survivorship. Use the data to create patient personas that can inform providers on how to best communicate with different types of patients and further support provider communication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

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

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.



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

## 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.

# 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

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.





## IDEAS FOR IMPLEMENTING THE ELEMENTS OF PCCC

*"Medicine killed my cancer but people saved my life."*

*Patti Rogers @rallyhood on the importance of community in cancer care. #deliveringPCCC*

### 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.

### 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.



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

## 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*

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

## 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.



## 1 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.

### 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 psychosocial 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

### Assumptions

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

### Integration

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

### Outcomes

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

*"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.



# CONCEPTUALIZED MODELS OF PCCC

# 2

THIS IS GROUP 2'S MODEL.

## 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

*The elephant in the room:  
"The way we pay for cancer care doesn't incentivize the type of care patients want"*  
@sfuldnasso #deliveringPCCC heather wajer @heatherwajer

## 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





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://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



- 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.

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

## 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](http://LIVESTRONG.org).