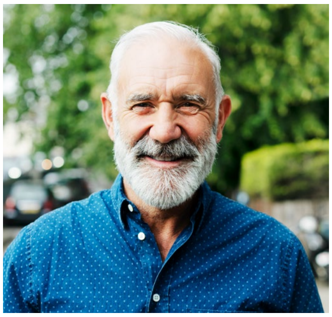



RTI REPORT


Key Initiatives






Highlighting recent work
(2020 – 2023)

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WELCOME

The Cancer Support Community's **Research and Training Institute (RTI)** was founded in 2008 with a commitment to engage, understand, learn from, and support people impacted by cancer.

Today, the **RTI is a leader in cancer psychosocial research**. By elevating patient and caregiver voices through research, we aim to:

- Understand the cancer experience and impact
- Enhance cancer care
- Guide program development
- Influence health-related policy

In this report, we highlight recent RTI initiatives from 2020 - 2023, which are driven by both **comprehensive enduring needs** in the cancer community, such as quality of life, access to care, and financial impact, as well as **focused emerging needs**, such as those related to COVID-19 and evolving approaches in cancer care, like biomarker testing.

This report will focus on three research approaches:

Capturing Lived Experiences: Survey Research

Creating New Measures of the Cancer Experience

Examining Real World Impact

We will start each section by tell you more about **HOW we approach this work**. We will then provide specific examples that include:

- **THE OPPORTUNITY:** Why is this work needed?
- **WHAT WE DID:** How did we complete the work?
- **WHAT WE LEARNED:** What are some key learnings?

To the many cancer patients, survivors, and caregivers who have partnered with us, we say
THANK YOU FOR TRUSTING US
to share your experiences and use them to better the future of cancer care and support.

Please visit the **resource page** at the conclusion of this report to see the types of resources that Cancer Support Community has to offer you.

Capturing Lived Experiences

Survey Research Highlights

How do we do survey research?

Review scientific literature to see what existing research tells us

Engage patients, caregivers, providers, and other experts to develop survey

Submit to institutional review board (IRB) to ensure research is ethical

Share survey opportunity through vast network of recruiting partners

Capture participant responses in secure environment

Analyze data and determine findings

Disseminate findings through publications and presentations

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BIOMARKER TESTING: PATIENT EXPERIENCES

A **biomarker** is a sign of disease or abnormal function that can be measured in your blood, tissue, or bodily fluid. In cancer, these biomarkers can be proteins, genes, or gene mutations, which may help to determine the best treatment for you.

Learn more HERE.

THE OPPORTUNITY:

Biomarker testing in oncology is becoming the standard-of-care. We know that biomarker testing affects patients' treatment and prognosis, and can improve health outcomes,[1,2,3] so it is important for us to develop a better understanding of biomarker testing experiences.

WHAT WE DID:

We conducted an online survey with 436 adults with breast, colorectal, and lung cancer who were diagnosed in 2018 or later. Participants were recruited through advocacy partners and through an online survey panel.

Participants answered questions about their biomarker testing experiences, including:

- Their familiarity with biomarker testing
- If they had biomarker testing during cancer care, and if so, what type
- Problems they experienced during biomarker testing
- How they learned and communicated about biomarker testing

BIOMARKER TESTING: PATIENT EXPERIENCES

WHAT WE LEARNED:

52% of participants were at least somewhat familiar with biomarker testing terminology, while 48% were slightly or not at all familiar.

85% of participants had biomarker testing, 9% did not have testing, and 6% were unsure if they had testing.

37% of participants reported no problems with their biomarker testing. Those with breast cancer were *more* likely to report no problems than those with lung or colorectal cancer.

The **most commonly reported problems** across cancer types were:

1) Difficulty understanding results
2) Long wait between test and results
3) Difficulty with scheduling the test

60% of participants talked with their medical oncologist about biomarker testing. Participants were also likely to talk with their primary care physicians (39%), family or friends (32%), and cancer support groups (27%).

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THE IMPACT OF COVID-19

THE OPPORTUNITY:

The COVID-19 pandemic continues to threaten the health and well-being of those living with a cancer diagnosis. Cancer patients and survivors have unique needs and areas of concern as a result of COVID-19, and the full impact of the pandemic on the cancer community, including delays in cancer screening and cancer care, remains to be seen.[4,5,6]

WHAT WE DID:

We conducted online surveys with around 1,000 adults living with a cancer diagnosis at multiple time points throughout the COVID-19 pandemic.

- **Time 1** Sep-Dec 2020
- **Time 2** Mar-Apr 2021
- **Time 3** Jun-Jul 2021
- **Time 4** Sep-Oct 2021
- **Time 5** Jun-Jul 2022

Participants answered questions about their COVID-19 experiences, including:

- COVID testing, diagnosis, and vaccination
- Shifts in treatment procedures and cancer-care
- Primary fears and concerns about COVID-19

THE IMPACT OF COVID-19

WHAT WE LEARNED:

Testing and vaccination rates increased over time. At Time 5 (June-July 2022), most survey respondents were fully vaccinated and had received at least one COVID-19 booster shot.

	% Tested for COVID	% Tested COVID +	% Fully Vaccinated	% Boosted 1 or more	% Not Vaccinated
Time 1	49%	3%	NA	NA	NA
Time 2	64%	4%	43%	NA	30%
Time 3	74%	8%	82%	NA	12%
Time 4	76%	13%	91%	26%	7%
Time 5	**86%**	**25%**	**96%**	**86%**	**4%**

Of those who received a COVID-19 booster (*n*=353), they *agree* or *strongly agree* that they are **now more likely to leave the house for:**

- medical reasons (66%)
- acquiring basic essentials (65%)
- social reasons (59%)

THE IMPACT OF COVID-19

WHAT WE LEARNED:

Disruptions in cancer care decreased at each timepoint, with 40% reporting any type of disruption at Time 1 and 18% at Time 5.

	Any type of disruption to cancer care	Routine screening	Imaging service (x-ray, MRI, etc.)	Lab services	Cancer treatment	Supportive services (OT, PT, etc.)
Time 1	40%	10%	13%	12%	5%	6%
Time 2	21%	9%	5%	6%	3%	1%
Time 3	16%	7%	5%	4%	<1%	2%
Time 4	17%	6%	4%	4%	2%	3%
Time 5	18%	6%	5%	3%	3%	2%

Importantly, **6% of participants still indicated a delay in routine screening at Time 5**, which can result in delay of diagnosis and required cancer care, highlighting the ongoing impact of COVID-19.

Half of participants (49%) reported **use of telehealth in 2022**. As such, we plan to continue to investigate telehealth use in the cancer community in the coming years.

THE IMPACT OF COVID-19

WHAT WE LEARNED:

The **top three concerns remained consistent** across the time points, with concern being highest at Time 1 (Sep-Dec 2020). At Time 5 (Jun-Jul 2022), most people are still expressing significant concern (being *somewhat* to *extremely* concerned) in these top three areas.

1

Others' lack of adherence to **safety recommendations** in public (like wearing masks)

Time 1: 86%

Time 5: 74%

2

Getting sick because I am a cancer survivor or patient

Time 1: 77%

Time 5: 65%

3

Worrying about a **loved one's health**

Time 1: 75%

Time 5: 58%

To learn more about **the psychological impact of the COVID-19 pandemic** on the cancer community, see our recently published paper HERE

CANCER SUPPORT
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CANCER EXPERIENCE REGISTRY

CANCER EXPERIENCE REGISTRY REDESIGN

THE OPPORTUNITY:

Over the next decade, more people will be diagnosed with cancer than ever before, and many are living longer with cancer as treatments extend life. At the same time, navigating care is becoming more and more complex. Despite the great need for actionable information about quality of life and care experience among people impacted by cancer, few large, data sources exist outside of academic settings.

CSC recognized the need to capture the lived experience of today's cancer patients, survivors, and caregivers, bringing to light unmet needs and gaps in care, by redesigning and sustaining the *Cancer Experience Registry* (CER).

CANCER EXPERIENCE REGISTRY REDESIGN

WHAT WE DID:

For more than 10 years, CSC has been expanding an online program of surveys with a major change in 2021. The relaunch of the new surveys included a revised baseline survey, follow-up surveys, and spotlight surveys.

Cross-Sectional

examining relationships at a single point in time

Longitudinal

collecting prospective data

Dyadic

capturing data from patient and caregiver pairs

Subgroup Analyses

segmenting the data in different ways (e.g., by diagnosis, region, age)

As of April 2023, over **2600 patients and 600 caregivers** have participated in the CER sharing insights that can provide CSC and the broader cancer community with actionable information to improve support services, enhance cancer care, and influence healthcare policy.

CANCER EXPERIENCE REGISTRY REDESIGN

WHAT WE LEARNED: *Patients and Survivors*

Quality of Life & Distress

44% were at risk for clinically significant levels of anxiety or depression

About **1 out of 2** were moderately to very seriously concerned with exercising/being physically active

Side Effects & Symptoms

Nearly **3 out of 10** were moderately to very seriously concerned about managing side effects of treatment

35% were moderately to very seriously concerned with thinking clearly (e.g., ‘brain fog’ or ‘chemo brain’)

Treatment Decision-Making

57% did not feel prepared to make cancer treatment decisions

Nearly **3 out of 5** did not feel knowledgeable about each cancer treatment option before making a decision

Financial Impact

1 out of 3 used up or depleted their savings to pay for medical costs

77% did not feel knowledgeable about the financial impact of each cancer treatment option

Practical Concerns

30% experienced delays or barriers to accessing cancer care or treatment

1 out of 3 were moderately to very seriously concerned with changes in work, school, or home life

CANCER EXPERIENCE REGISTRY REDESIGN

WHAT WE LEARNED: *Cancer Caregivers*

Caregiver Roles

54% reported **always** attending medical visits with the patient

1 out of 4 reported providing constant care

Treatment Decision-Making

9 out of 10 wanted help understanding patients' cancer, treatment options, and prognosis

88% were quite a bit or very much involved in talking to the patient about care goals and treatment preferences

Impact on Employment

43% went in late, left early, or took time off to provide care

Nearly **1 out of 5** went from working full-time to part-time, or cut hours

Quality of Life & Distress

2 out of 3 reported worse emotional/mental health due to caregiving

62% reported worse sleep due to caregiving

Caregiver Needs

31% wanted help balancing work, life, family, and caregiver demands, **but did not receive it**

2 out of 3 wanted help managing their negative feelings, **but did not receive it**

CANCER EXPERIENCE REGISTRY REDESIGN

WHAT WE LEARNED: *Spotlight Survey*

In August 2022, we conducted a spotlight survey of CER patients on barriers to accessing mental health care. A total of 658 **who reported an emotional or mental health concern since cancer diagnosis** took part.

Many patients with cancer are not receiving the mental health care they need.

60%

of those in distress were **not** referred to a mental health professional by their cancer care team

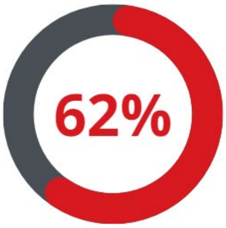
40%

of those who wanted mental health support did **not** receive it

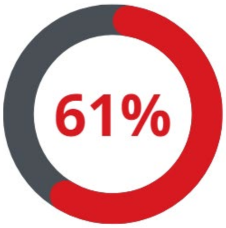
Supportive care can be an important part of the cancer experience.

While **48% were prescribed depression or anxiety medication**, many respondents wanted other support in improving emotional well-being.

Exercise Classes



Meditation Classes



Nutrition Programs

Support Groups

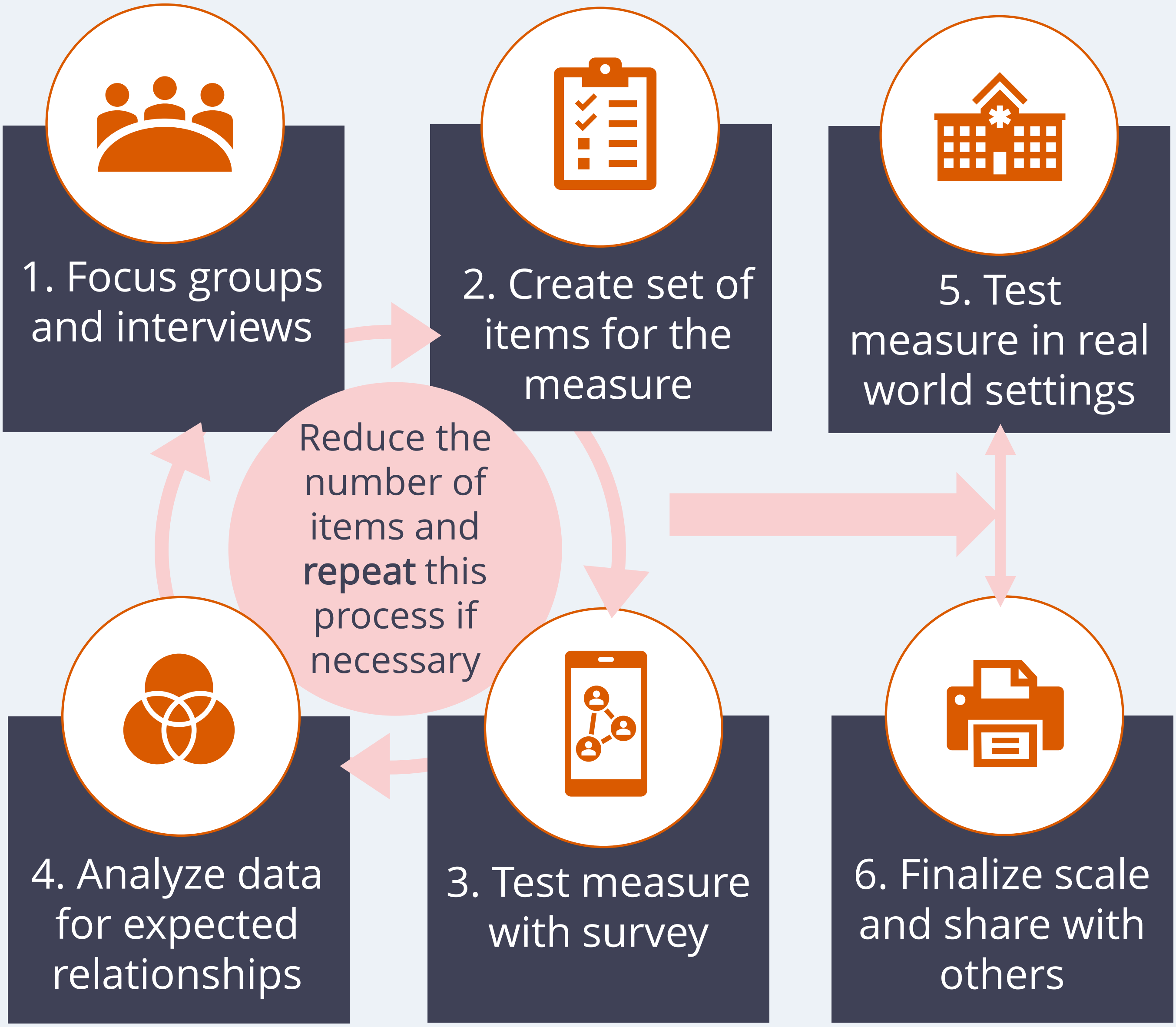
Creating New Measures of the Cancer Experience

How do we create new measures of the cancer experience?

Some of the steps for creating new measures of the cancer experience are similar to what we do in our survey research. However, we also want to take extra steps to make sure the new measure:

- ✓ Captures the concept we *want* it to measure
- ✓ Accurately reflects the patient experience, including the range and wording of items

Some critical steps in measure development include:



1. Focus groups and interviews

2. Create set of items for the measure

3. Test measure with survey

4. Analyze data for expected relationships

Reduce the number of items and **repeat** this process if necessary

5. Test measure in real world settings

6. Finalize scale and share with others

VOICE VALUED OUTCOMES IN THE CANCER EXPERIENCE
A MEASURE OF THE CANCER SUPPORT COMMUNITY

THE OPPORTUNITY:

Perceived control can influence patients’ ability to achieve important care goals and can affect physical and mental well-being. Existing research shows that feelings of control can be changed and improved. While not all aspects of cancer can be controlled at all times, enhancing people's sense of control can positively impact their psychological well-being, hope, and resilience.[7,8,9]

WHAT WE DID:

We aimed to develop and validate a patient-centric measure of personal control over goals that are highly valued and relevant to cancer patients.

In 2022, we published a paper detailing our efforts in engaging over 1600 patients to develop, validate, and refine VOICE. The paper is available HERE.

VALUED OUTCOMES IN THE CANCER EXPERIENCE (VOICE)

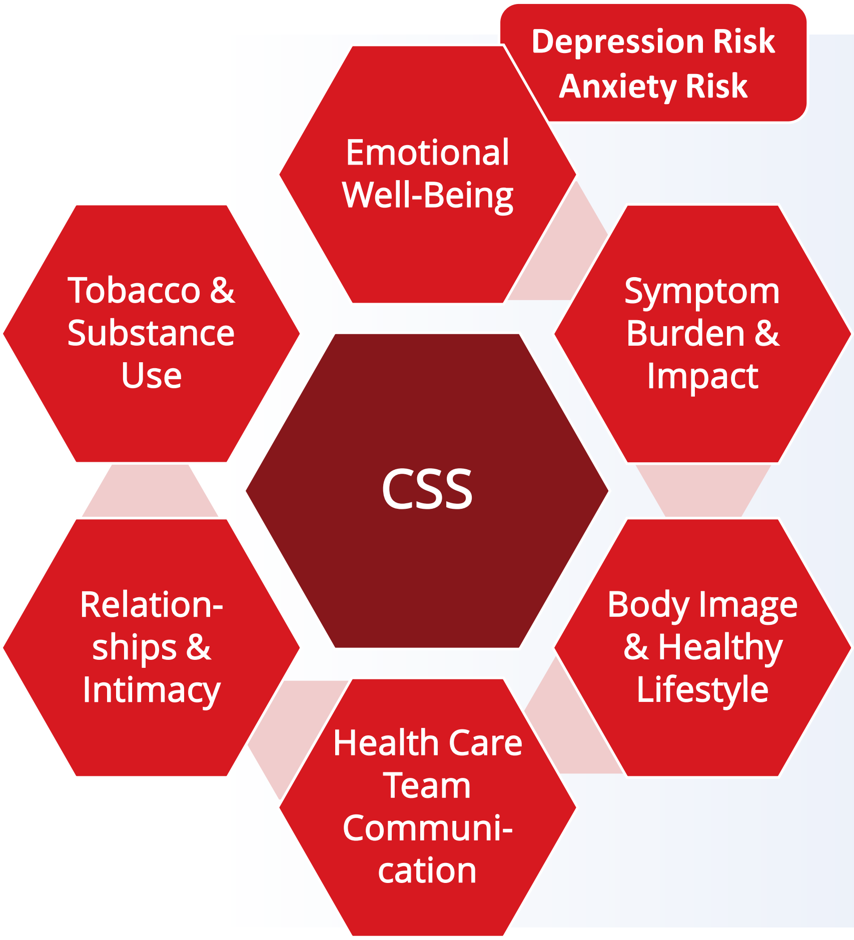
VOICE is a 21-item measure with seven content areas

WHAT WE LEARNED:

We found that patients’ sense of control and their hope are key components to their well-being. This is consistent with CSC’s Patient Empowerment Theoretical Framework.[10]

VOICE is positioned to not only help us better understand cancer patients' experiences, but also to measure the impact of programs that increase people's sense of control and empowerment.[10]

Distress screening is essential to cancer care,[11] but there are still improvements to be made. Since 2008, CSC has been investigating the feasibility and effectiveness of screening, referral, and follow-up for cancer-related distress and unmet needs through the development of the **CancerSupportSource (CSS)** program.

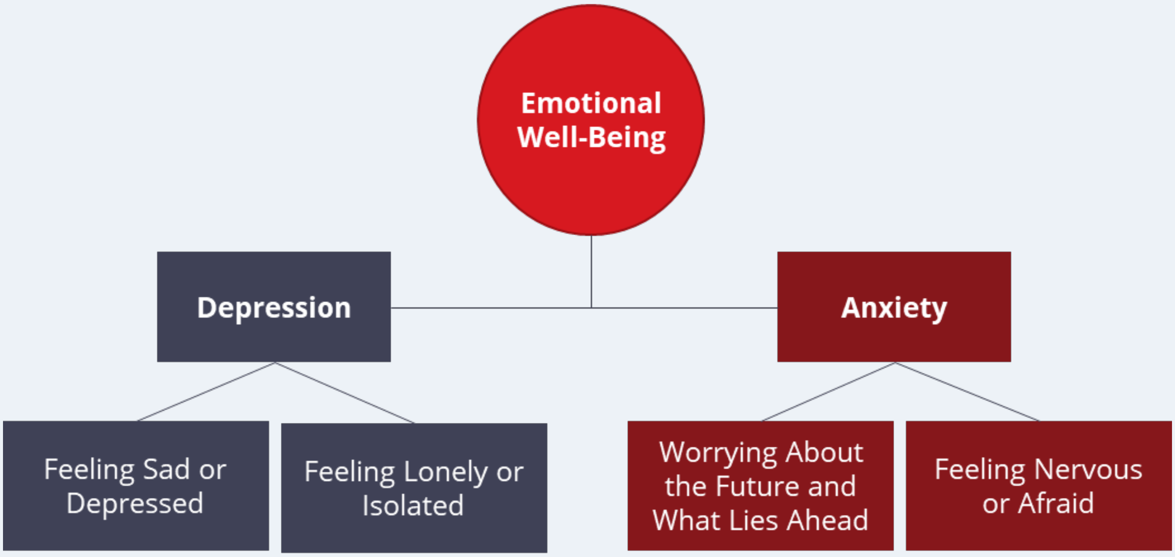


CSS is a 25-item measure with five content areas, plus a single item evaluating substance use

We want to ensure that <u>all</u> people impacted by cancer receive the support they need. As such, we tailored CSS to fit the unique needs of various groups impacted by cancer, including family and friend caregivers (CSS-Caregiver) and Spanish-speaking Latino and Hispanic individuals with cancer (CSS-Spanish).

CSS is a valid, flexible program that:

- ✓ automatically generates reports for clinicians and respondents that include tailored information based on respondents’ identified concerns
- ✓ links to free, accessible resources, which are provided by local CSC affiliates across the country
- ✓ flags respondents at risk for clinical levels of depression and anxiety



No screening tool alone can diagnose clinical depression or anxiety, but screening is an important step in identifying those in need of further follow-up evaluation and resources.

Through rigorous scale development and testing, we have found CSS measures to be reliable, valid, and multi-dimensional screening tools that can easily be integrated into cancer care across different groups.

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CANCER SUPPORT SOURCE

DISTRESS SCREENING FOR SPANISH-SPEAKING HISPANIC AND LATINO COMMUNITIES

Healthcare disparities exist for Hispanic and Latino individuals living in the U.S. Following a cancer diagnosis, Hispanic and Latino individuals face unique barriers to quality of life. Cultural factors such as language barriers, health literacy, and beliefs surrounding medicine are often a large barrier to closing the gaps between the physical needs of this population and providers' ability to deliver the support.[12]

THE OPPORTUNITY:

One way to bridge the gap in health care disparities is to increase access to distress screening, referral, and follow-up to people who are medically underserved. There is a lack of available distress screening and referral tools available for non-English speakers, including those in Spanish-speaking communities.[13]

WHAT WE DID:

Using gold-standard translation methods,[14,15] we created a cultural adaptation of CSC for use in Spanish-speaking Hispanic and Latino communities, **CancerSupportSource-Spanish** (CSS-Spanish), which was then tested in a sample of 210 respondents from Hispanic and Latino communities.

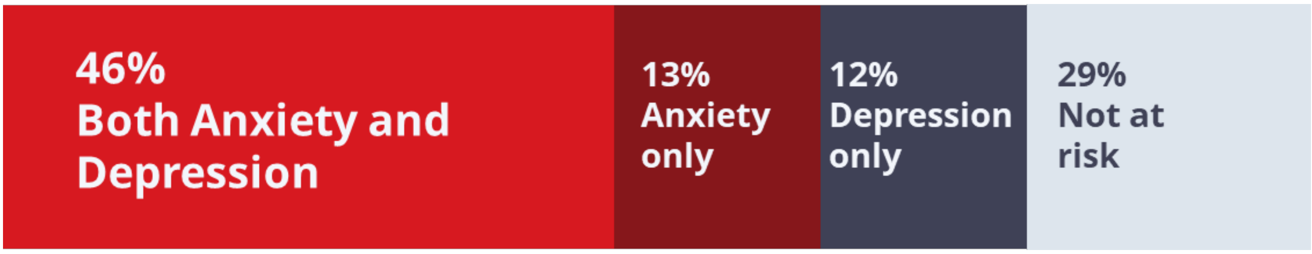
DISTRESS SCREENING FOR SPANISH-SPEAKING HISPANIC AND LATINO COMMUNITIES

CSS-Spanish
is a 25-item measure
with five content areas plus an optional item assessing substance use

WHAT WE LEARNED:

CSS-Spanish is a reliable, valid multidimensional distress screener that rapidly assesses needs of Hispanic and Latino individuals. Embedded depression and anxiety risk flags can help quickly identify those in need of more support and resources.

Based on a sample of 210 respondents, we identified many at risk for clinical levels of anxiety and depression.



CAREGIVER DISTRESS SCREENING

THE OPPORTUNITY:

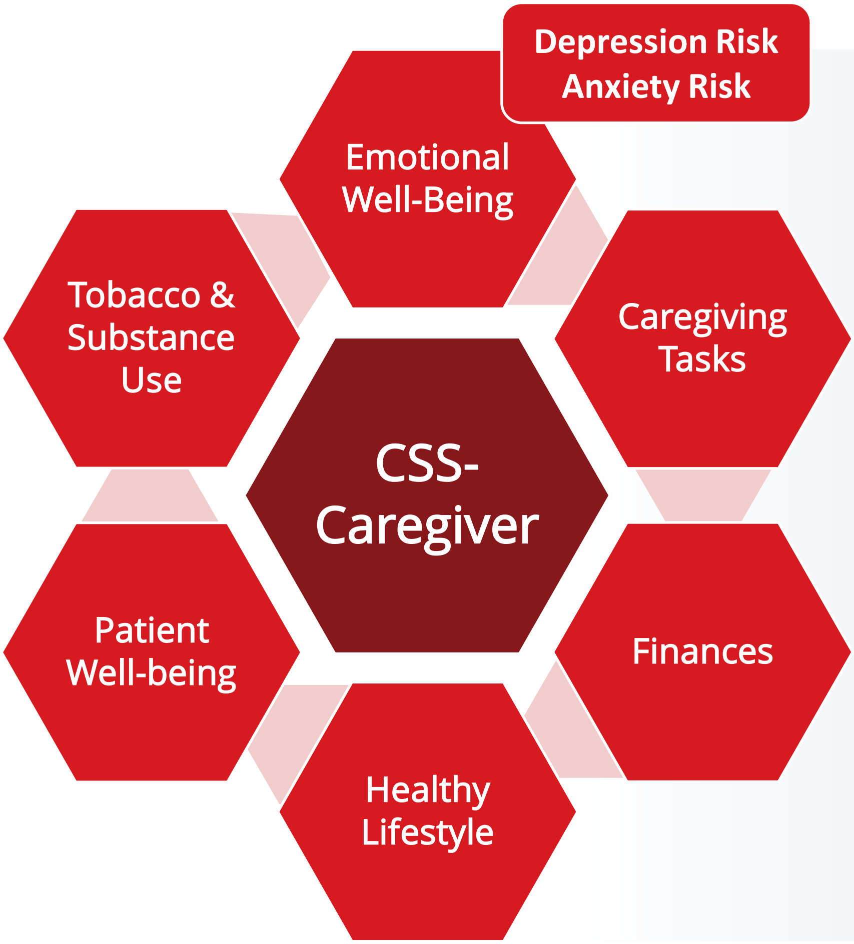
Caregiver distress affects the quality of life and health of caregivers, as well as patient well-being. Rapid advancements in cancer treatment place caregivers in a critical patient and family support role before, during, and after treatment, substantively increasing risk for caregiver distress.[16,17,18]

Supportive care is underutilized by cancer caregivers due to **systemic gaps in access and lack of caregiver time.**

WHAT WE DID:

We developed **CancerSupportSource-Caregiver** (CSS-Caregiver), the first and only cancer caregiver distress screening, referral, and support program for family and informal cancer caregivers.

CAREGIVER DISTRESS SCREENING



Depression Risk
Anxiety Risk

Emotional Well-Being

Caregiving Tasks

Finances

Healthy Lifestyle

Patient Well-being

Tobacco & Substance Use

CSS-Caregiver

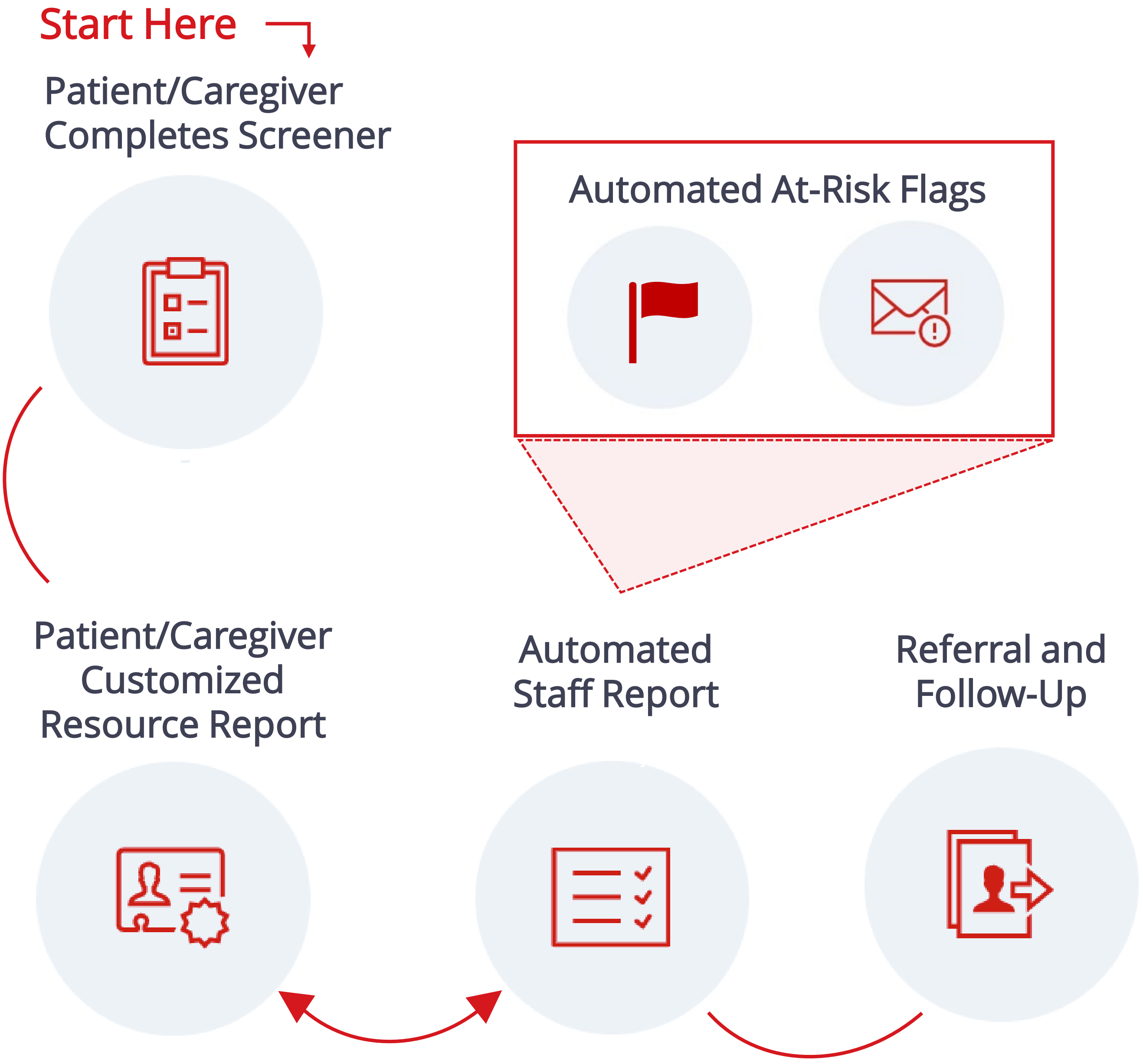
CSS-Caregiver is an 18-item measure with five content areas, plus an optional item evaluating substance use

The goal is to **rapidly identify and respond to unmet caregiver needs across key areas of life**, thereby better enabling the caregiver to navigate care and treatment, practice self-care, and provide support for the unique needs of the patient.

In 2023, we published a paper detailing our efforts in engaging over 400 caregivers to develop, validate, and refine CSS-CG. The paper is available HERE.

Examining Real World Impact

How do we promote whole-person care with comprehensive distress screening?



Start Here

Patient/Caregiver Completes Screener

Automated At-Risk Flags

Patient/Caregiver Customized Resource Report

Automated Staff Report

Referral and Follow-Up

Supporting all steps in the cancer care experience

Healthcare Utilization & Cost

Health-Related Quality of Life

Treatment Adherence

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IMPACT OF DISTRESS SCREENING ON CARE UTILIZATION

THE OPPORTUNITY:

When cancer patients' distress is not addressed, it can lead to worse quality of life. Unsupported distress can also have a negative financial impact on patients and on institutions.[19] Depressed cancer patients tend to have more emergency department visits and inpatient hospital admissions,[20,21] and cancer patients with mental health diagnoses have higher healthcare costs.[22,23]

Psychosocial distress screening can **rapidly identify patients' unmet needs and connect them to needed support.** However, there is little research on the impact of distress screening on healthcare utilization and cost.

WHAT WE DID:

We partnered with Orlando Health Cancer Institute, a Network Partner of CSC.

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ORLANDO HEALTH

We sought to understand the impact of distress screening with CancerSupportSource for breast cancer patients getting care there by looking at existing data records for 148 breast cancer patients over 2 years in a **retrospective study design**.

IMPACT OF DISTRESS SCREENING ON CARE UTILIZATION

KEY LEARNINGS:

Patients screened with CSS who utilized Cancer Support Community supportive services at Orlando Health **within one year following screening**:

had **50%** fewer ED visits

And were more likely to access:

- integrative medicine department services
- patient and family counseling services
- financial counseling

There were no statistically significant differences in 2-year healthcare costs, after controlling for age and race/ethnicity.

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IMPACT OF CSS-CAREGIVER ON CAREGIVER WELL-BEING

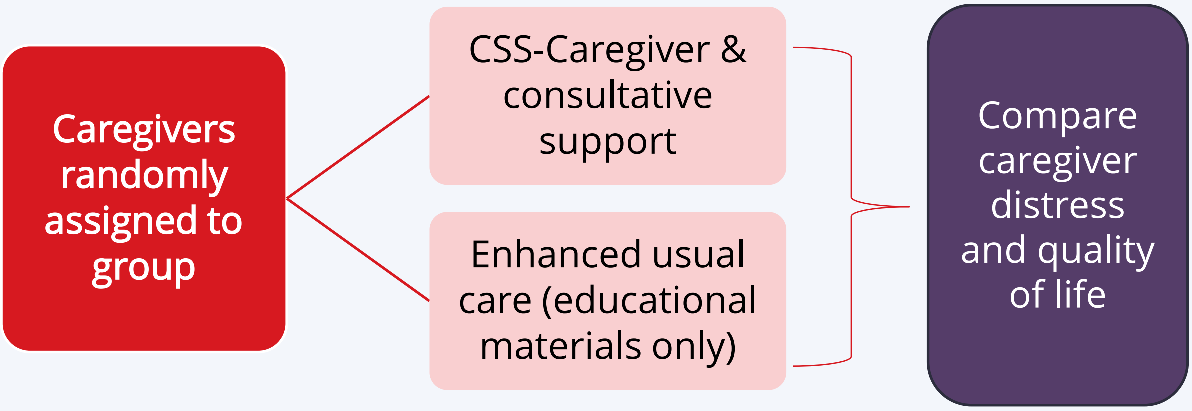
THE OPPORTUNITY:

Distress screening is standard practice among cancer patients, yet there are few routine comprehensive distress screening programs for cancer caregivers, who typically report higher distress than patients.[24, 25] Screening may increase caregivers' access to supportive services and improve well-being.[26]

Memorial Sloan Kettering
Cancer Center

WHAT WE DID:

We partnered with researchers at Memorial Sloan Kettering Cancer Center to understand the feasibility of using CSS-Caregiver at a large comprehensive cancer center, using a **randomized controlled design**.



Caregivers randomly assigned to group

CSS-Caregiver & consultative support

Enhanced usual care (educational materials only)

Compare caregiver distress and quality of life

IMPACT OF CSS-CAREGIVER ON CAREGIVER WELL-BEING

KEY LEARNINGS:

Among **75 caregivers** presenting with a patient with cancer to a cancer surgery center, CSS-Caregiver was:

- ☑ **Feasible**, with 95% completing the screening
- ☑ **Efficient**, connecting caregivers to wanted support
- ☑ **Acceptable**, helping caregivers feel cared for and integrated into cancer care

When compared to enhanced usual care of educational materials only, caregivers completing CSS-CG screening and referral program had **significantly improved emotional well-being.**

CSC RESOURCES

Cancer Support Community Homepage – You can navigate to all our free resources and support services from this page.

Find a CSC/GC location near you

Helpline – Call 888-793-9355 or chat a community navigator, resource specialist, or licensed social worker. Open Monday-Friday: 9:00 a.m.-8:00 p.m. ET & Saturday: 9:00 a.m.-5:00p.m. ET.

MyLifeLine – Create a private website where you can document your cancer experience and invite your friends and family to join and support you through your journey. Connect with others like you through discussion boards monitored 24/7 by licensed mental health professionals.

Virtual Programs – Visit our virtual home and navigate through each room to access award-winning articles, videos, and podcasts on a variety of topics.

RTI Page – Visit our research page and explore some of our active projects, presentations and publications, and more.

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