

# **CancerSupportSource™-Spanish: Development of a multidimensional distress screening measure for Spanish-Speaking Hispanic and Latino individuals living with cancer**

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# Disclosures



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**Fortune:**

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**Zaleta:**

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**Hendershot:**

None to disclose.

# Our Mission

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.



# Our Reach

**CSC and Gilda's Club centers as well as hospital partnerships in the U.S. and around the world.**



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## **OPENING IN 2023-2024**

CSC SW COLORADO

# CancerSupportSource™-Spanish

## Outline and Objectives



## Outline

- I. Project Overview**
- II. Screener Development**
- III. Screener Validation**
- IV. Program Implementation**
- V. Summary**

## Objectives

### Workshop attendees will learn:

- Importance of distress screening in cancer care and related disparities
- Crucial steps in screener development, translation, and validation
- Utility of the CancerSupportSource™ program for assessing and addressing unmet needs in cancer

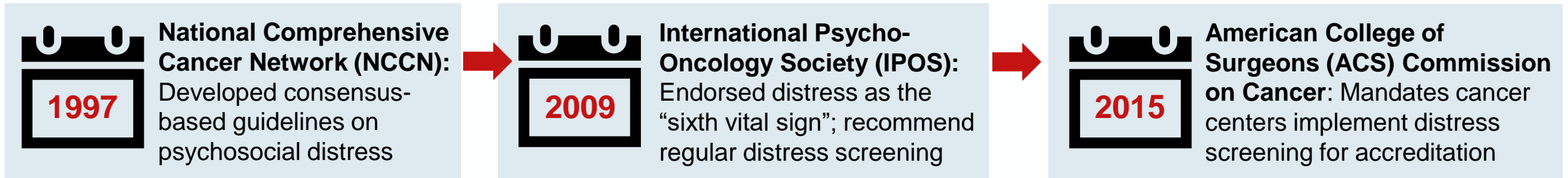
# I. Project Overview

# CancerSupportSource™-Spanish

## Project Overview



## The Need



- In the US, Hispanic and Latino individuals living with cancer experience significant disparities, yet have limited access to culturally and linguistically competent distress screening and support that can improve their well-being

## The Program

- CancerSupportSource™(CSS), a distress screening and referral program, identifies unmet needs of people with cancer and links them to resources and support
- We developed and validated a **Spanish-language version (CSS-Spanish)** to better serve Hispanic and Latino communities and promote health equity

# CancerSupportSource-Spanish

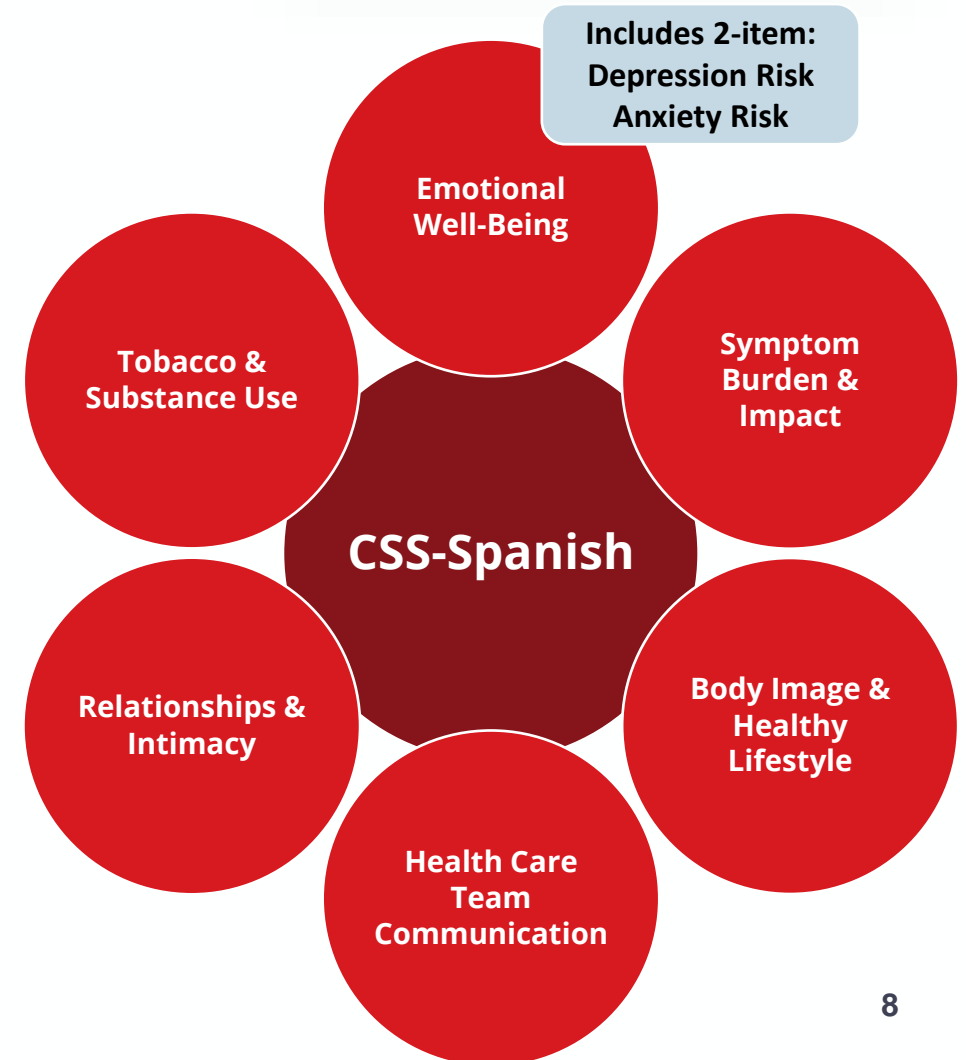
## Screeners Summary

We created **CSS-Spanish**, a 25-item, psychometrically robust measure of distress and unmet needs.

### CSS-Spanish screens for:

- Concerns across key areas of life
- Risk for clinically significant depression and anxiety
- Desired support and resource needs

**CSS-Spanish is delivered via a web-based platform to support screening, referral, and follow-up**

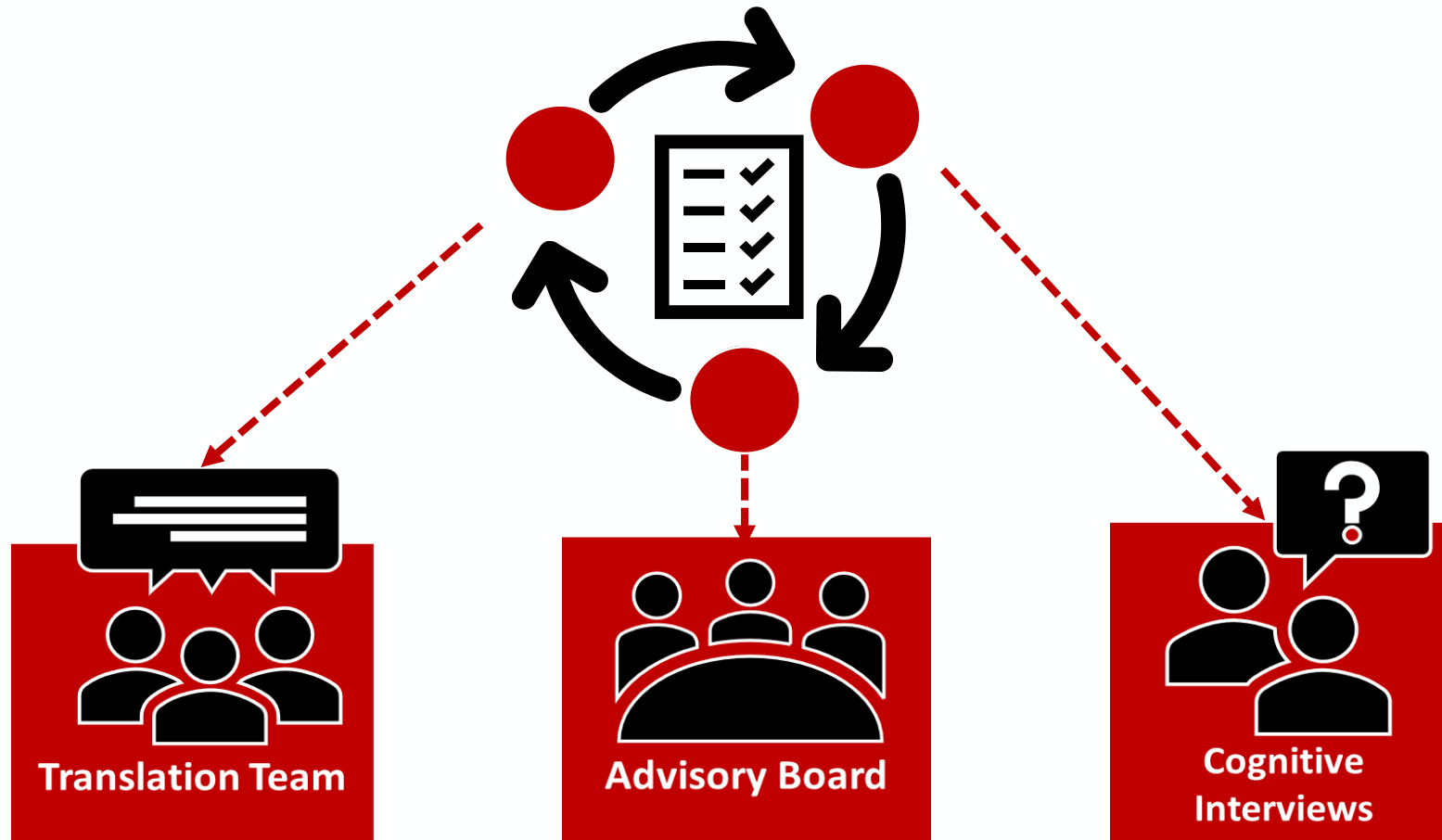




# II. Screener Development

# CancerSupportSource-Spanish

## Linguistic and Cultural Relevance



**Iterative process of review**, including multiple voices, capturing various cultural backgrounds and types of expertise

Do screener items capture the needs of diverse cultures within Hispanic and Latino communities?

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## Gold Standard Translation Process



### Preparation

Creation and examination of content



### Forward Translation

Translation from English to US Spanish by linguistic team



### Back Translation

Translation from US Spanish to English by new linguistic team



### Reconciliation

Quality manager compares translations and reconciles content to ensure conceptual equivalence between languages



### Review and Harmonization

Additional quality control step comparing multiple versions of the translation and identifying content for further review

- Informed by World Health Organization (WHO) and Professional Society for Health Economics and Outcomes Research (ISPOR)
- Consideration for most common Spanish dialects in US (Mexican and Caribbean Spanish)
- Unique translators at each stage of the process, all native speakers or subject matter experts

# CancerSupportSource-Spanish

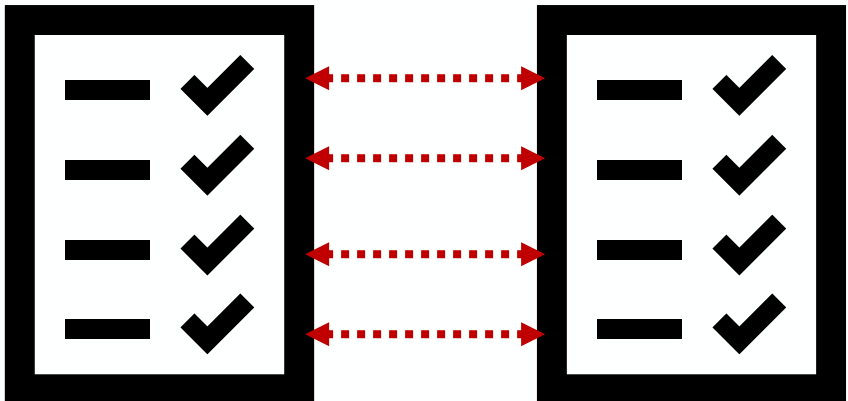
## Cognitive Interviews



### Expert interview team of three individuals

- All native Spanish language speakers
- Research Analysts and Methodologists with Masters or PhDs (Public Policy, Sociology, Human Development & Family Studies)
- Interviews conducted virtually via phone or Zoom

Patient feedback on content and different versions of item wording



*What were you thinking about when I asked this question?  
Can you give me some examples of what this means?  
Which makes more sense to you?*



# CancerSupportSource™-Spanish

## Items and Factors



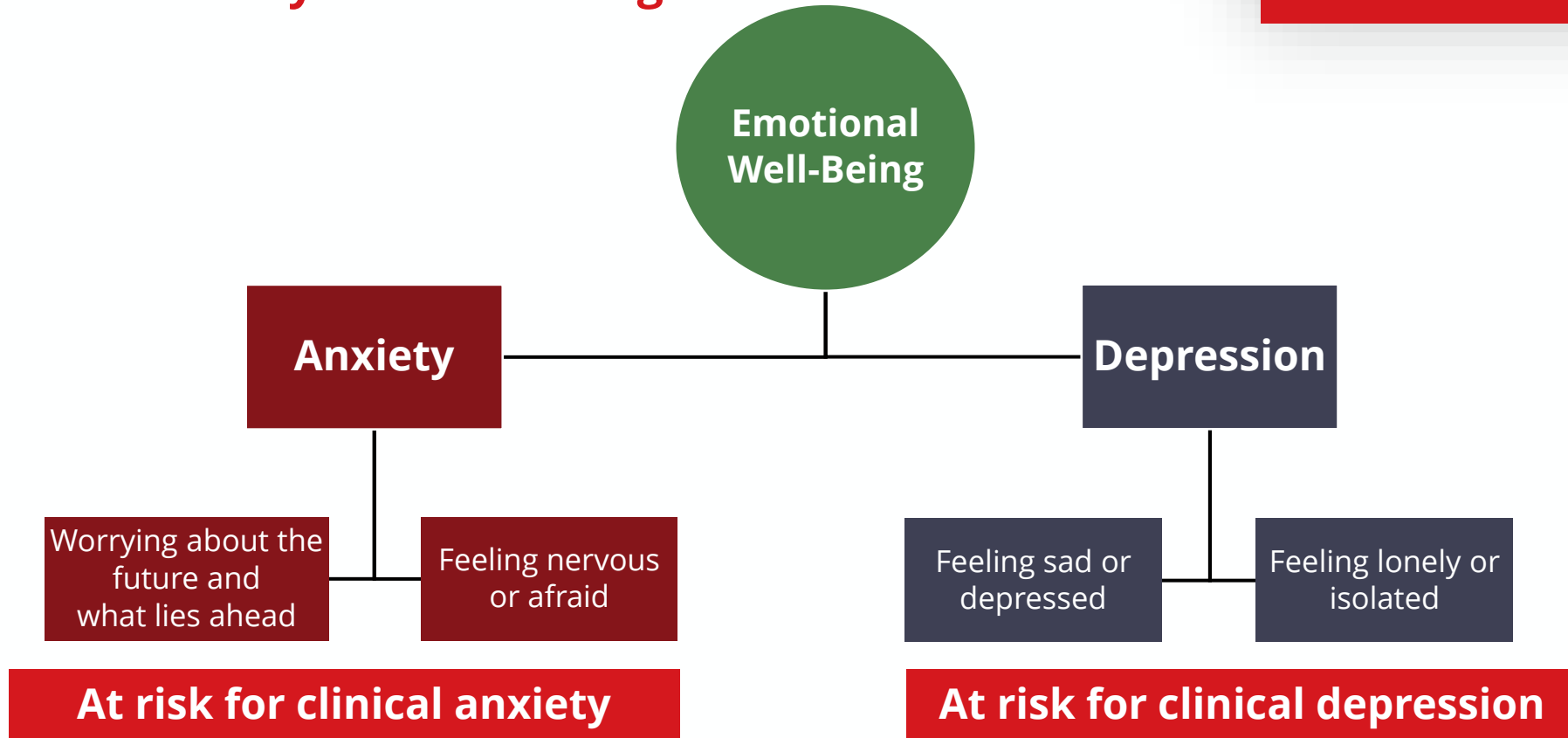
Factor	Item (Spanish)	Item (English)
<b>Emotional Well-Being</b>	Sentirse irritado Sentimientos de tristeza o depresión <sup>‡</sup> Sentirse nervioso o con temor <sup>‡</sup> El futuro y lo que se espera <sup>‡</sup> Sentirse solo o aislado <sup>‡</sup> El seguro médico o las preocupaciones por el dinero La familia, los niños o los amigos Encontrarle un propósito y sentido a la vida	Feeling irritable Feeling sad or depressed <sup>‡</sup> Feeling nervous or afraid <sup>‡</sup> Worrying about the future and what lies ahead <sup>‡</sup> Feeling lonely or isolated <sup>‡</sup> Health insurance or money worries Worrying about family, children and/or friends Finding meaning and purpose in life
<b>Symptom Burden &amp; Impact</b>	Desplazarse o moverse (caminar, subir escaleras, levantarse, etc.) Problemas para dormir Cambios o alteraciones en el trabajo, la escuela o la vida en el hogar El transporte para llegar a su tratamiento y sus citas Dolor o molestias físicas Sentirse demasiado cansado para hacer las cosas que necesita o quiere hacer Manejo los efectos secundarios del tratamiento (náuseas, hinchazón, etc.) Pensar con claridad (p. ej., problemas de concentración, memoria, o fatiga mental)	Moving around (walking, climbing stairs, lifting, etc.) Sleep problems Changes or disruptions in work, school or home life Transportation to treatment and appointments Pain and/or physical discomfort Feeling too tired to do the things you need or want to do Managing side effects of treatment (nausea, swelling, etc.) Thinking clearly (e.g., "chemo brain," "brain fog")
<b>Body Image &amp; Healthy Lifestyle</b>	Alimentación y nutrición Su imagen física y sus sentimientos respecto a la manera cómo se ve Cambio de peso reciente (aumento o pérdida de peso) Hacer ejercicio y estar físicamente activo	Eating and nutrition Body image and feelings about how you look Recent weight change (gain or loss) Exercising and being physically active
<b>Health Care Team Communication</b>	La comunicación con su médico Toma de decisiones acerca del tratamiento	Communicating with your doctor Making a treatment decision
<b>Relationships &amp; Intimacy</b>	Intimidad, función sexual o fertilidad Problemas en su relación con su esposa(o)/ pareja	Intimacy, sexual function and/or fertility Problems in your relationship with your spouse/partner
<b>Tobacco, Alcohol, or Substance Use</b>	Consumo de tabaco o drogas (por su parte o de alguien en su hogar)	Tobacco, alcohol, or other substance use

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**Note:** <sup>†</sup> = 2-item depression risk; <sup>‡</sup> = 2-item anxiety risk

# CancerSupportSource-Spanish

## Depression and Anxiety Risk Screening



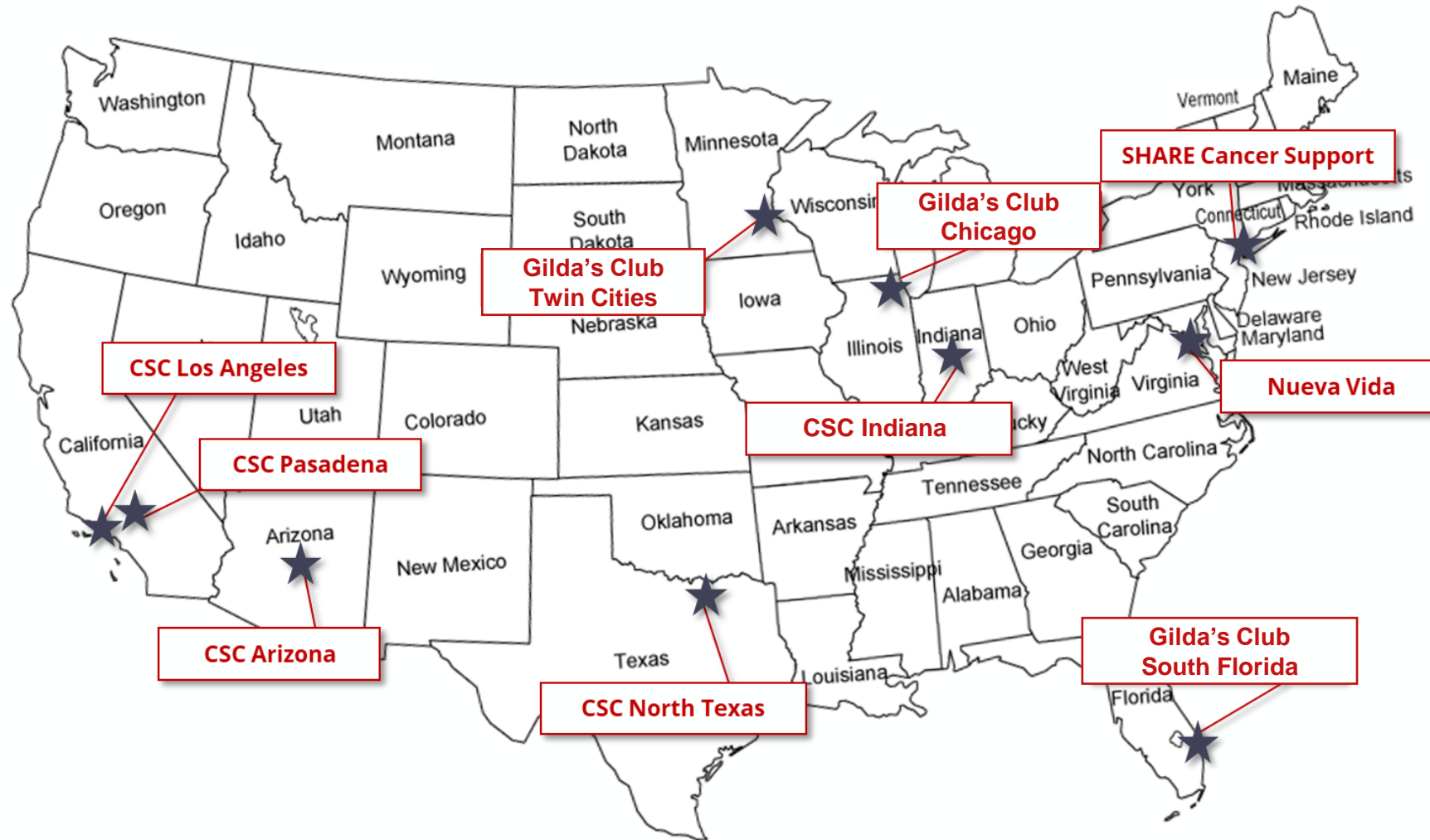
- Untreated depression and anxiety can have serious consequences
- Embedded within CSS-Spanish are subscales to flag people at-risk for clinical levels of depression and anxiety
- Staff are notified when a flag is activated and can provide appropriate follow-up



# III. Screener Validation

# CancerSupportSource-Spanish

## Validating the Screener



**210 participants** completed CSS-Spanish and comparison measures in an online survey conducted 11/2021 – 8/2022

### Recruitment occurred via:

- CSC National Platforms
- Cancer Experience Registry
- MyLifeLine online community
- CSC & GC Network partners
- Advocacy partners
- Nueva Vida
- SHARE
- National survey polling firm

Participants identified as more than a dozen Hispanic and Latino origins, with the largest groups including **Mexican (40%), Columbian (8%), Puerto Rican (8%), Cuban (7%), and Dominican (7%)**

# CancerSupportSource-Spanish

## Statistical Validation Results

### Internal reliability:

High internal **consistency** ( $\alpha=.95$ ) and test-retest **reliability** ( $r=.92$ ); individual factor ICCs  $\geq .79$

### Confirmatory Factor Analysis:

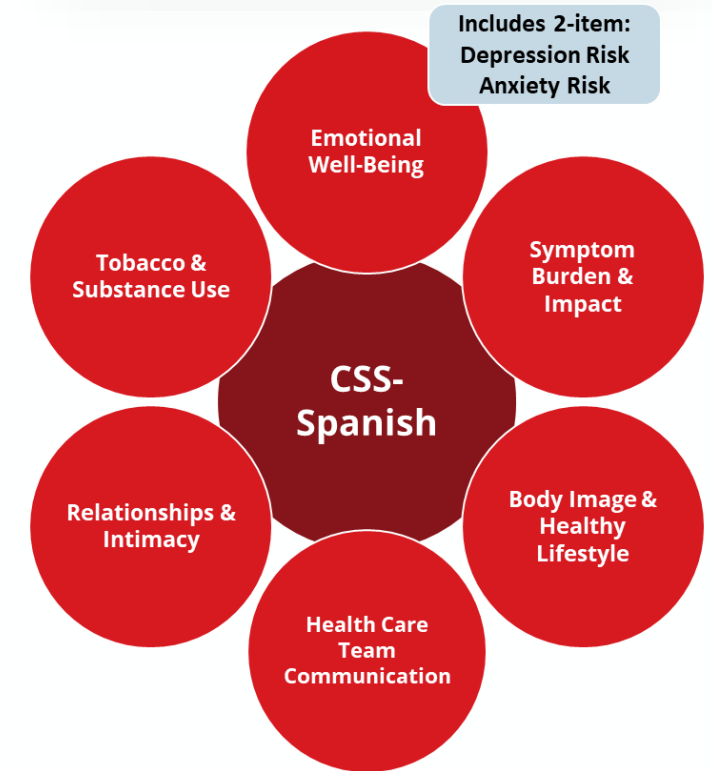
Good to acceptable **model fit**: RMSEA=0.08[CI = 0.069-0.086], SRMR=0.06, CFI=0.90, TLI=0.89,  $\chi^2=546.48$

### Scale correlations with comparison validation measures:

Strong and **statistically significant correlations** (absolute value of  $r > 0.50$ ;  $p < .05$ ) observed between total CSS-Spanish distress and all seven domains of PROMIS29 (depression, anxiety, social function, physical function, sleep disturbance, fatigue, pain interference), as well as PHQ-2, GAD-2, and NCCN Distress Thermometer

### Known groups validity:

**Greater total distress associated** with cancer recurrence ( $r=.24$ ,  $p < .001$ ), time since diagnosis ( $r=-.17$ ,  $p < .001$ ), metastatic status ( $t=4.150$ ,  $p < .001$ ), and active treatment ( $t=3.151$ ,  $p < .001$ )



### ROC Analysis

#### **2-item Depression**

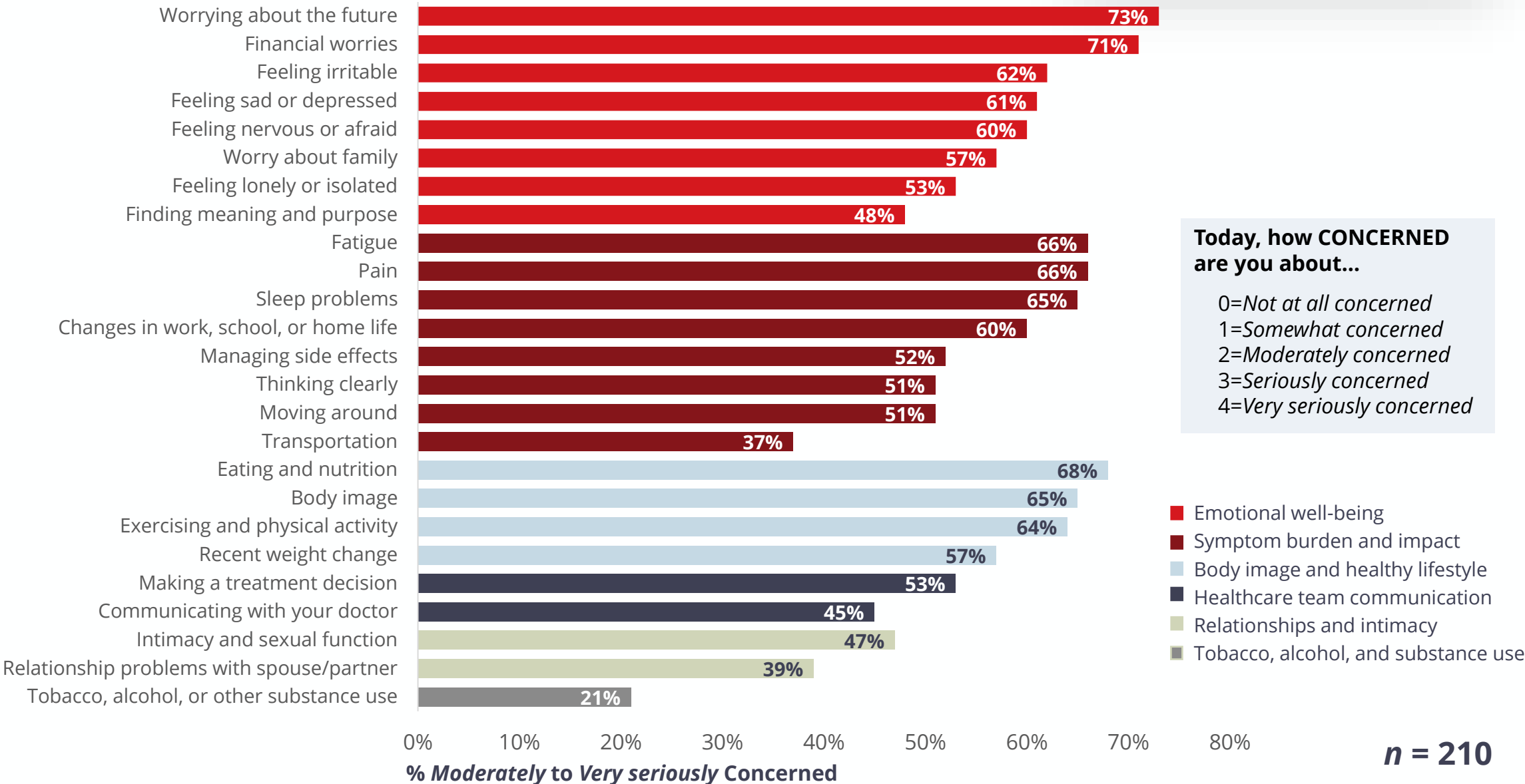
AUC=0.840; Sensitivity=0.84

#### **2-item Anxiety**

AUC=0.852; Sensitivity=0.90

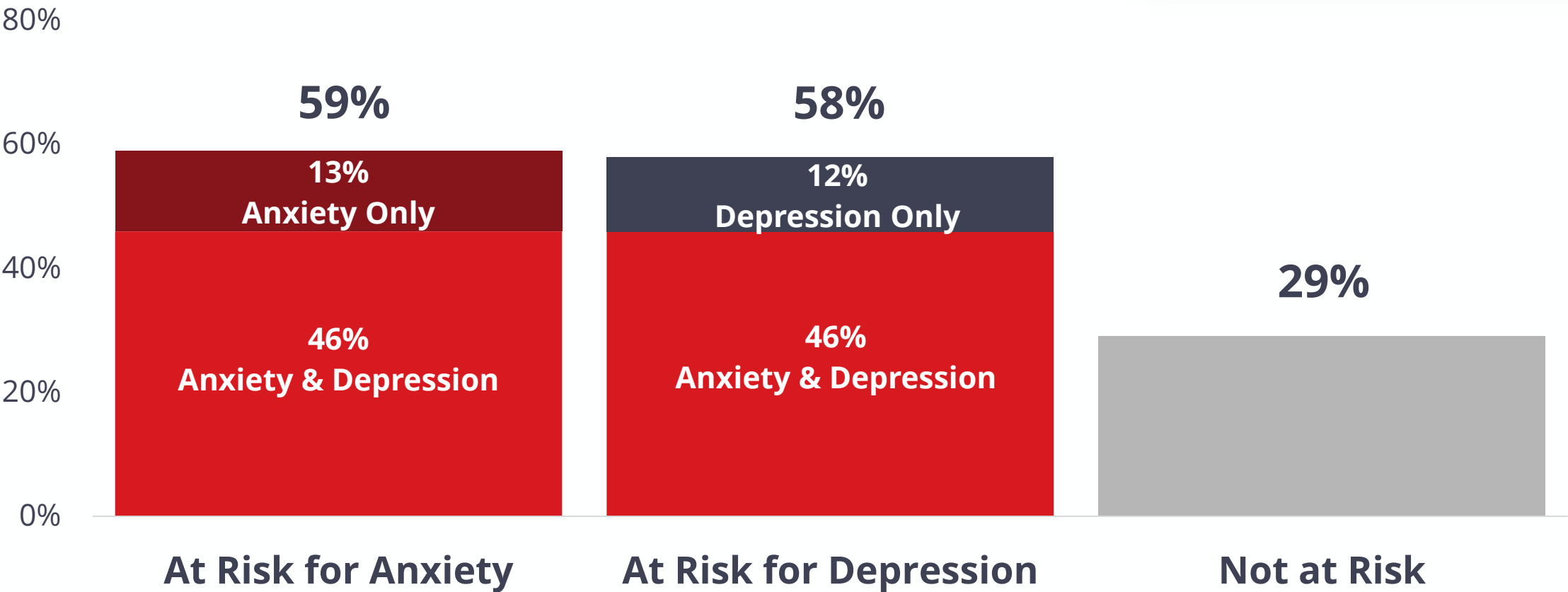
# CancerSupportSource-Spanish

## Participant Concerns



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## Depression and Anxiety Risk among Validation Participants



In our sample (N=210), 71% of respondents reported depression or anxiety at levels triggering a clinical “risk flag.” In the full program, staff receive an automatic notification so that persons at risk can receive needed follow-up.

# IV. Program Implementation



# How It Works

## CancerSupportSource-Spanish Distress Screening and Referral



★ Development and psychometric testing for this screener described in previous slides

# How It Works

## Respondent Completes Screener & Chooses Desired Support



### Respondent Completes Screener



Hoy, ¿cuán PREOCUPADO está sobre... Sentimientos de tristeza o depresión

☐ Nada

☒ Levemente

☐ Moderadamente

☐ Seriamente

☐ Muy serio

Sentimientos de tristeza o depresión: Díganos cómo podemos brindarle ayuda

☐ Hablando con un miembro del personal

☐ Proporcionándole recursos escritos o en línea

☐ No es necesario tomar ninguna acción

# How It Works

## Customized and Automated Reports



### Respondent Customized Resource Report



#### Mi Plan Asistencial

Gracias por completar el Cuestionario de angustia de CancerSupportSource®. Este informe se creó especialmente para usted en función de sus respuestas. Es una guía para encontrar la información y los servicios que podrían serle más útiles en este momento. Revise los consejos y los materiales impresos y en línea proporcionados en este informe. Un miembro del personal con gusto repasará este informe con usted y le ayudará a encontrar más recursos.

Nombre: Victoria TEST  
Fecha de Nacimiento: 01/01/1990  
Fecha del Cuestionario: 01/06/2023

#### Imagen Corporal y Estilo de Vida Saludable

No es raro preocuparse por los cambios en su aspecto físico. Algunos de estos cambios serán temporales y otros más duraderos. El aumento de peso, la caída del cabello y los cambios en la piel suelen reportarse con frecuencia durante el tratamiento del cáncer. Ha identificado sus inquietudes relacionadas con la imagen corporal y un estilo de vida saludable.



Aquí hay algunos recursos en línea relacionados que puede querer

Su imagen física y sus sentimientos respecto a la manera como se ve  
[https://files.mycarereport2.com/22S\\_SU\\_IMAGEN\\_FISICA\\_Y\\_SUS\\_SENTIMIENTOS\\_RESPECTO\\_A\\_LA\\_MANERA\\_COMO\\_SE\\_VE.pdf](https://files.mycarereport2.com/22S_SU_IMAGEN_FISICA_Y_SUS_SENTIMIENTOS_RESPECTO_A_LA_MANERA_COMO_SE_VE.pdf)

#### Bienestar Emocional

Es normal sentir una gran diversidad de emociones en respuesta a un diagnóstico de cáncer, durante el tratamiento del cáncer y después de finalizar el tratamiento. El cáncer puede provocar emociones como tristeza o depresión, ansiedad, miedo y preocupación por el futuro. Si bien algunos problemas pueden ser leves, otros pueden agravarse e impedir que se sienta esperanzado o que sienta que controla su vida. Es importante que obtenga el apoyo que necesita para poder cuidarse mejor. Ha identificado sus inquietudes relacionadas con su bienestar emocional.



Aquí hay algunos recursos en línea relacionados que puede querer

Sentimientos de tristeza o depresión  
[https://files.mycarereport2.com/22S\\_SENTIMIENTOS\\_DE\\_TRISTEZA\\_O\\_DEPRESION.pdf](https://files.mycarereport2.com/22S_SENTIMIENTOS_DE_TRISTEZA_O_DEPRESION.pdf)



#### My Support Care Plan

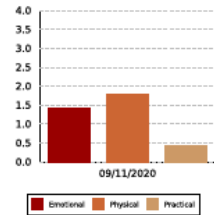
##### Survey Results

Name: Ellen SAMPLE  
Date of Birth: 01/01/1990  
Date of Screening: 09/11/2020  
Distress score: 30/100  
Risk for depression: 3/8  
Risk of anxiety: 3/8

Concern	Screening 09/11/20	Action Required
Today, how CONCERNED are you about... Eating and nutrition	1. Slightly	Information
Today, how CONCERNED are you about... Feeling irritable	1. Slightly	Information
Today, how CONCERNED are you about... Moving around (walking, climbing stairs, lifting, etc)	2. Moderately	
Today, how CONCERNED are you about... Communicating with your doctor	0. Not at all	
Today, how CONCERNED are you about... Sleep problems	4. Very Seriously	Talk, Information
Today, how CONCERNED are you about... Changes or disruptions in work, school or home life	1. Slightly	
Today, how CONCERNED are you about... Feeling sad or depressed	2. Moderately	Talk, Information
Today, how CONCERNED are you about... Transportation to and from treatment	0. Not at all	
Today, how CONCERNED are you about... Pain and/or physical discomfort	1. Slightly	
Today, how CONCERNED are you about... Body image and feelings about how you look	0. Not at all	
Today, how CONCERNED are you about... Feeling nervous or afraid	2. Moderately	Information
Today, how CONCERNED are you about... Worrying about the future and what lies ahead	4. Very Seriously	Information
Today, how CONCERNED are you about... Making a treatment decision	0. Not at all	
Today, how CONCERNED are you about... Intimacy, sexuality and/or fertility		
Today, how CONCERNED are you about... Feeling lonely or isolated	1. Slightly	Information
Today, how CONCERNED are you about... Health insurance or money worries	0. Not at all	
Today, how CONCERNED are you about... Problems in your relationship with your spouse/partner	0. Not at all	
Today, how CONCERNED are you about... Feeling too tired to do the things you need or want to do	2. Moderately	Information
Today, how CONCERNED are you about... Managing side effects of treatment	3. Seriously	
Today, how CONCERNED are you about... Worrying about family, children and/or friends	0. Not at all	
Today, how CONCERNED are you about... Recent weight gain or loss	3. Seriously	
Today, how CONCERNED are you about... Exercising and being physically active	1. Slightly	Information
Today, how CONCERNED are you about... Tobacco or drug use	0. Not at all	

##### Top 5 Concerns

Today, how CONCERNED are you about... Sleep problems 4  
Today, how CONCERNED are you about... Worrying about the future and what lies ahead 4  
Today, how CONCERNED are you about... Managing side effects of treatment 3  
Today, how CONCERNED are you about... Recent weight gain or loss 3  
Today, how CONCERNED are you about... Moving around (walking, climbing stairs, lifting, etc) 2



### Automated At-Risk Flags



# How It Works

## Staff Facilitate Referrals and Follow-Up

### Review Referrals

Making a treatment decision

Status: In progress

Patient:	peyton SAMPLE	Referral date:	12/13/2022
Form name:			
Doctor:			
MRN:	-	Email:	peytonyopmail@yopmail.com
Birthdate:	01/01/1990	Mobile phone:	
Support assigned:	Test MYCARE		

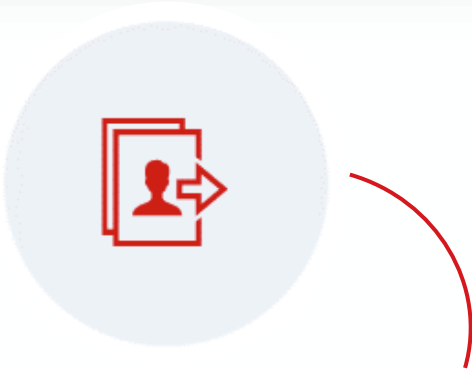
Status History Update

Date	Reminder Date	Notes	User
12/13/2022 14:13 PM	-	Add detailed case notes here.	Peyton LENGACHER
12/13/2022 14:12 PM	-	Assigned by Peyton LENGACHER	Test MYCARE

Automated Report Tracks Referrals History and Status



Referral and Follow-Up



### My Support Care Plan

Name peyton SAMPLE (Male)  
Date of Birth: 01/01/1990  
Date of Screening: 12/13/2022  
Distress score: 31/76

### Referrals History

Date	Referral	Assigned To	Status	History
12/13/22	Sleep problems	Test MYCARE	Resolved	- Assigned by Peyton LENGACHER - Add detailed case notes here. - Referral closed by Peyton LENGACHER
12/13/22	Making a treatment decision	Test MYCARE	In progress	- Assigned by Peyton LENGACHER - Add detailed case notes here.
12/13/22	Worrying about family, children and/or friends	Test MYCARE	In progress	- Assigned by Peyton LENGACHER - Add detailed case notes here.
12/13/22	Risk for depression	Test MYCARE	In progress	- Assigned by Peyton LENGACHER - Add detailed case notes here.

# V. Summary

# CancerSupportSource-Spanish

## Summary



CSS-Spanish is a **psychometrically robust measure of psychosocial distress** among Hispanic and Latino individuals with cancer

CSS-Spanish was created using **gold-standard methods** for translation and an **iterative process** of testing that included feedback from Spanish-speaking Hispanic and Latino individuals living with cancer and a project advisory board

In full program implementation, it can **facilitate distress screening, referral, and follow-up** to rapidly assess unmet needs and enhance well-being

Benefits of CSS-Spanish can be **optimized when implemented with a strong case management system and access to Spanish-language community resources**



*Thank you*

[efortune@cancersupportcommunity.org](mailto:efortune@cancersupportcommunity.org)