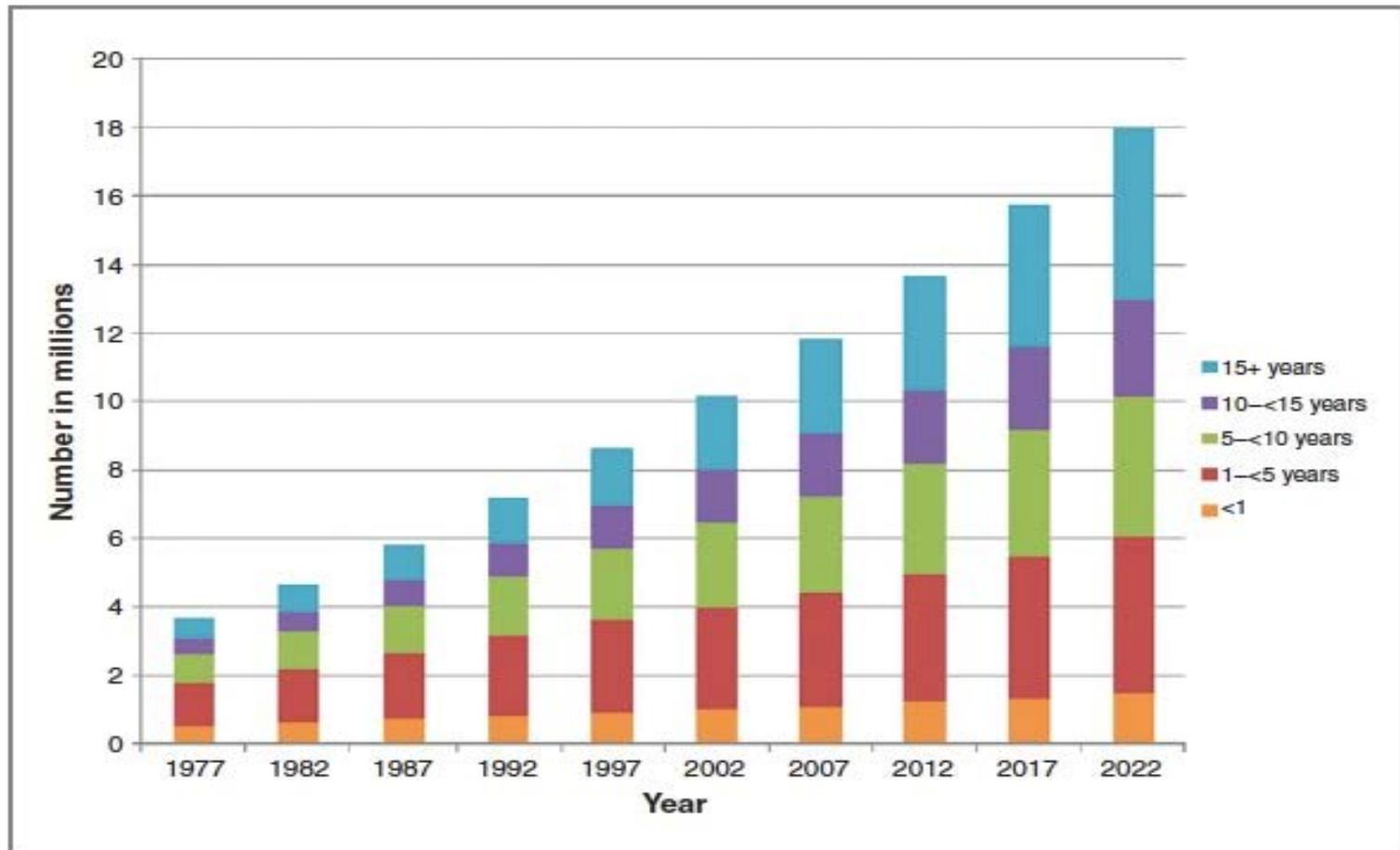




# The Cancer Survivor Profile (CSPro): Developing a Decision Aid for Cancer Survivors

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# Breast Cancer Survivors



8%

8%

# SCP: Status to Date

	<b>American Society of Clinical Oncology (2009)</b> American Society of Clinical Oncology	<b>Journey Forward (2008)</b> National Coalition for Cancer Survivorship, UCLA Cancer Survivorship Center, Wellpoint, Inc., Genentech	<b>Lance Armstrong Foundation (2012)</b> Lance Armstrong Foundation	<b>Prescription for Living (2012)</b> American Cancer Society, Oncology Nursing Society, National Coalition for Cancer Survivorship, American Journal of Nursing, University of Pennsylvania School of Nursing
<b>Health Services</b>				
Health Information	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Health Care Access	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Communication	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Economic Barriers	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
<b>Symptoms</b>				
Fatigue	<b>X</b>	GR	"Are you experiencing fatigue (overwhelming physical, mental or emotional exhaustion)?"	"Persistent fatigue"
Depressive Symptoms	<b>X</b>	<b>X</b>	<b>X</b>	"Major depression" "Depression"
Anxiety	<b>X</b>	<b>X</b>	<b>X</b>	"Anxiety disorder" "Anxiety"
Pain	GR	GR	"Development of pain, numbness or tingling in the arm on the side of the surgery?" "Pain, numbness or tingling of the arm on the side of the radiation?"	"New pain (bone, abdomen, head and neck)"
Fear of Recurrence	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Body Image	<b>X</b>	<b>X</b>	"How would you rate the cosmetic appearance of the affected breast compared to your other breast?" "Do you have changes in the color or texture of your skin as a result of therapy?"	<b>X</b>
Fertility Distress	<b>X</b>	<b>X</b>	GR	<b>X</b>

X = Not addressed; GR = General recommendations in Survivorship Care Plan

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<b>Function</b>				
Social Relationships	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Work	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>
Sexual Function	<b>X</b>	GR	"Experience sexual changes (vaginal dryness, shrinkage, painful intercourse)?"	"Psychosexual problems"
Cognitive Function	<b>X</b>	GR	<b>X</b>	<b>X</b>
Sleep Disturbance	<b>X</b>	<b>X</b>	<b>X</b>	"Sleep problems"
<b>Health Behaviors</b>				
Smoking	<b>X</b>	<b>X</b>	GR	"Smoking cessation"
Alcohol Consumption	<b>X</b>	<b>X</b>	GR	<b>X</b>
Physical Activity	<b>X</b>	<b>X</b>	GR	"Physical activity"
Diet	<b>X</b>	<b>X</b>	GR	"Nutrition and healthy weight management"
Weight Change	<b>X</b>	"Patient's BMI Pre-treatment Post-treatment" "Patient's Weight Pre-treatment Post-treatment"	GR	"Weight gain > 10 lbs" "Weight loss > 10 lbs" "Nutrition and healthy weight management"

X = Not addressed; GR = General recommendations in Survivorship Care Plan

# Meeting a Need: Prior 2 Years

- Develop the Cancer Survivor Profile (CSPro)
  - Brief, multi-dimensional measure:
    - Symptom burden
    - Function
    - Health behaviors
    - Health services
- Establish psychometric properties of CSPro
  - Factor Structure
  - Reliability
  - Validity

# CSPro Development

## Quantitative Search

1

### Conduct systematic searches

- Search engines: PubMed, PsychINFO, Embase, CINAHL, Web of Science

2

### Review search results

- R1 conducted searches and retrieved titles and abstracts
- R1 and R2 independently reviewed titles and abstracts
- R3 settled R1 and R2 discrepancies
- R1 retrieved selected articles

3

### PROMIS item selection

- R1 recorded participant descriptions of constructs
- R1 and R3 selected PROMIS items consistent with participant descriptions in qualitative studies

### CONSTRUCTS

*Fatigue*

*Pain*

*Depressive symptoms*

*Anxiety*

*Cognitive function*

*Sleep*

*Sexual function*

*Social relationships*

*Alcohol consumption*

R = Reviewer

# CSPro Development

## Qualitative Search

Social	Fatigue	Anxiety	Cognitive	Sexual Function	Pain	Sleep	Dep. Symp.
Support	Tired	Anxiety	Memory	Lack of interest	Joint	Disturban-ce	Depression
Significant other	Fatigue	Worry	Executive function	Libido	Burn	Quantity	Isolation
Lonely	Energy	Fear	Concentra-tion	Pain	Sharp	Tired	Tearful
Emotional	Pervasive	Health anxiety	Word finding	Attractive	Intensity	Night awake	Sad
Change	Rest	Irritability	Processing speed		Mobility	Naps	Upset
Relating	Unpredicta-ble	Anxiety attacks	Fog			Restless	Loss of interest

# Breast Cancer Survivor Profile

Symptom Burden	Function	Health Behaviors	Health Services
Fertility distress (6)	Cognitive (6)	Diet (6)	Communication (6)
Anxiety (6)	Social (6)	Exercise (3)	Health competence (6)
Depressive symptoms (6)	Sleep (6)	Cigarette smoking (4)	Health information (6)
Fatigue (6)	Sexual (4)	Alcohol (5)	Economic (4)
Pain (5)	Work (6)		
Fear of recurrence (6)			
Body image (3)			

Case ID: 1234567  
Date of Birth: \_\_\_\_\_

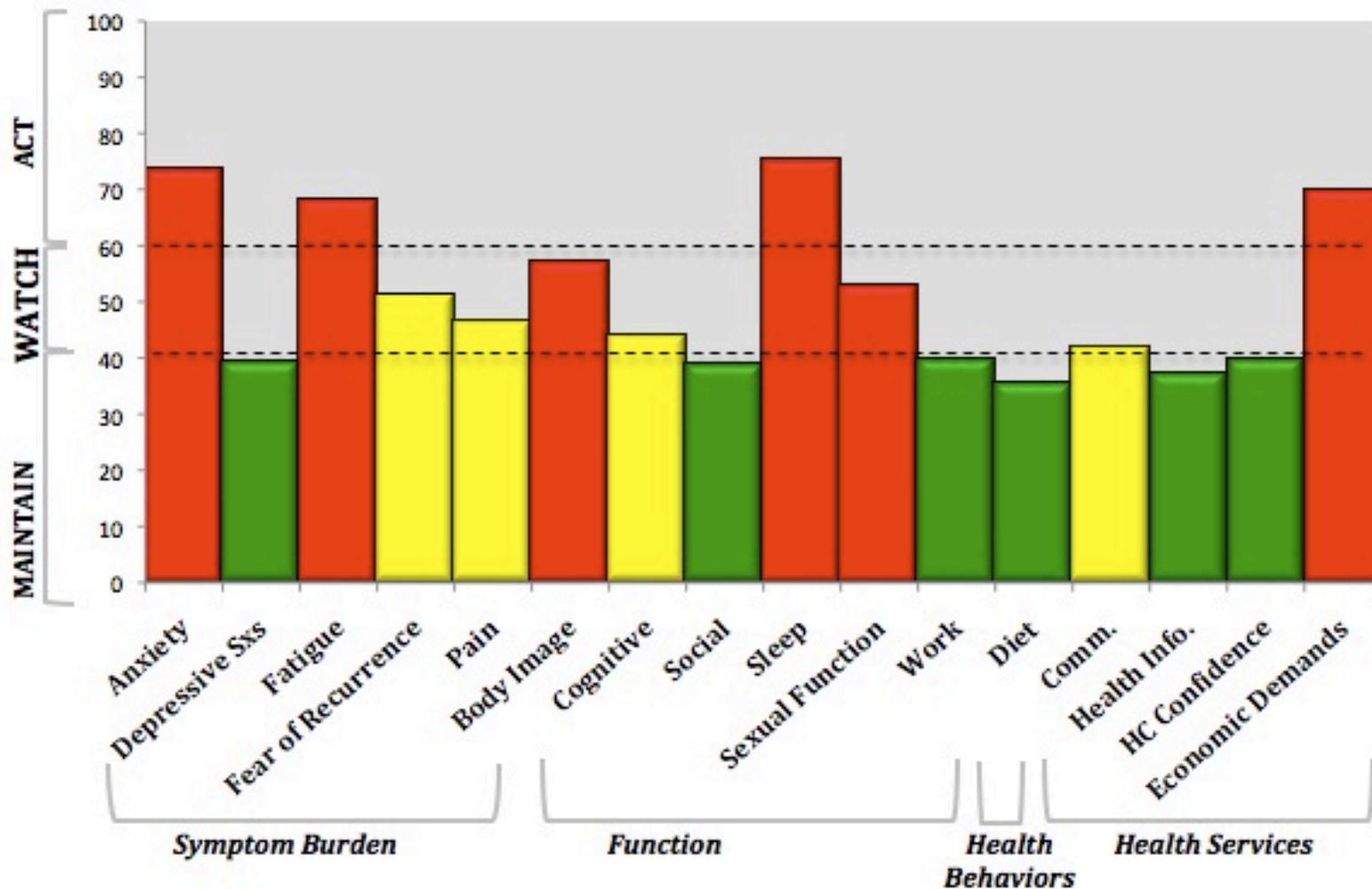
Gender: Female  
Survivor Type: BCS

# My Cancer Survivor Profile

BMI: \_\_\_\_\_

Current Height: \_\_\_\_\_

Weight: \_\_\_\_\_



# Next Steps: The Murtha CSN Study

## Cancer Survivor Network: Project Overview

### Phase I

#### Program Development

1. Identify BCRC stakeholders
2. Work with BCRC stakeholders to:
  - Modify triage decision algorithms to align specific problem areas identified in the CSPro screening tool with appropriate recommendations
  - Confirm usual care
3. Develop:
  - CSPro and Output for use on a tablet.
  - Manual of operations for both the intervention group and the control group.

0 months

### Phase II

#### Usability & Feasibility

1. Conduct a usability, feasibility, and face validity assessment of the CSN
  - Evaluate perceived credibility and expectancy of Intervention and Usual Care (based on description).
  - Evaluate participant and staff time required to complete all elements of the study
  - Evaluate usability & utility of each component of CSN
2. Improve the CSN and manual of operations based on feedback
3. Prepare for RCT

3 months

### Phase III

#### RCT

1. Conduct Randomized Controlled Trial (RCT) comparing:
  - **Usual Care** (SCP + Symptom Checklist + Referrals/Recommendations/Resources)
  - **SCP + CSN** (CSPro Screen Tool, Referrals/Recommendations/Resources, Problem Solving Training, Access to troubleshooting phoneline)
2. Determine (Primary):
  - Self-Efficacy (Chronic Disease Self-Efficacy Scale)
  - Visits to MCC Breast Care and Research Center (CPT code)
  - Visits to outpatient clinics (Type, CPT code)
3. Determine (Secondary):
  - Anxiety (HADS-A)
  - Depressive symptoms (HADS-D)
  - Physical health (SF-36-PCS)
  - Mental health (SF-36-MCS)

6 months

2 years

