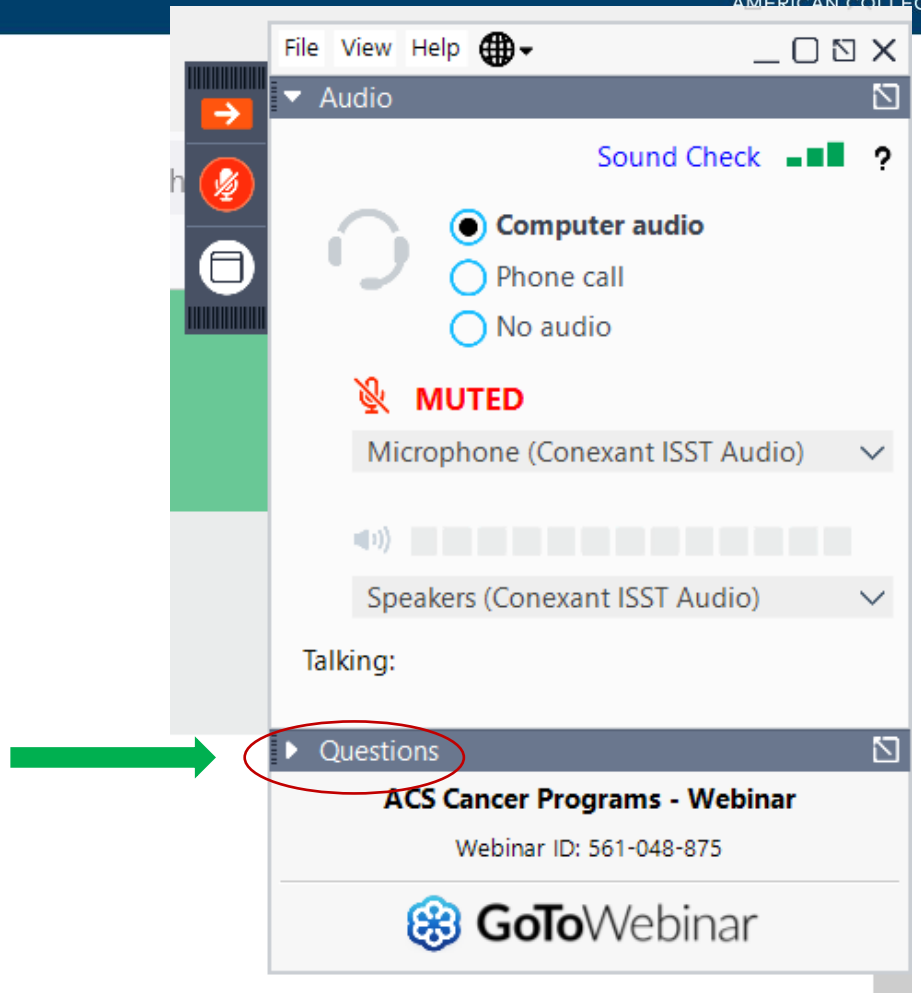
Commission on Cancer
American College of Surgeons

Breaking Barriers: Finding Community Resources to Address Barriers

April 5, 2023

Logistics

- All participants are muted during the webinar
- Questions – including technical issues you may be experiencing – should be submitted through the question pane
- Questions will be answered as time permits; additional questions and answers will be posted on the website
- Please complete the post-webinar evaluation you will receive via email



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Introducing our Moderator and Panelists

Dr. Laurie Kirstein, MD, FACS
Attending Breast Surgeon
Memorial Sloan Kettering Cancer Center
Associate Professor
Cornell University Medical College

Sarah Kerch
GW Cancer Center
Project Director, Comprehensive Cancer Control Technical Assistance

Shayla Scarlett
GW Cancer Center
Assistant Director, Community Outreach, Engagement, and Equity

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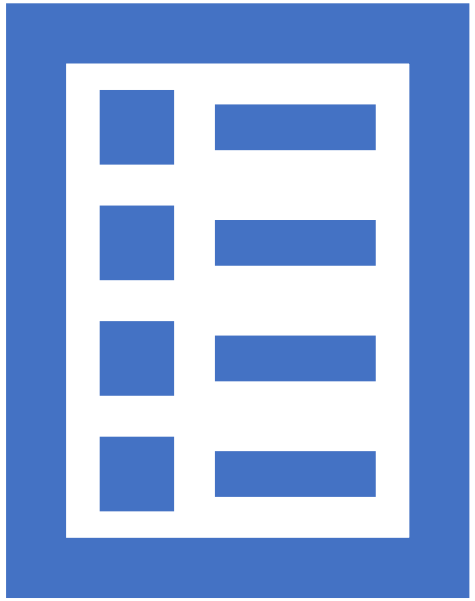
Agenda for today

- Breaking Barriers 101
- Unique Needs of Patients with Cancer
- The GW Cancer Control Toolkit
- Step 2 in Action: Successes, Challenges, and Considerations
- Q and A



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Breaking Barriers

Cancer PROGRAMS
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Complete Application ✓

Build a Team ✓

Released April 15
Due April 30

Submit Pre-survey and data metrics

Get Letter of Support from Radiation Team

You are Here

Begin Project

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Breaking Barriers: Begin Project

1. Begin tracking “no show” rates

   Through Radiation software programs, EHR reports, manually on excel tracking sheet, or any other custom way

2. Assess existing strategies for tracking and outreach to patients
   Do you currently call? Text? Email? Utilize a patient portal?
   What do you “do” with the information?

3. Evaluate internal workflow, assess for information technology needs
   Who is reaching out to patients to ask?
   Do you have scripted language for asking?
   Do you have a lexicon for reasons missed and a place to record those?

4. Complete a Community Asset Map to understand patient population, needs, and existing resources

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ACS CoC Commission on Cancer
American College of Surgeons

The Unique needs of patients with Cancer

Cancer and Psychological Burden

- About 30 to 50% cancer patients, and more than 60% of those with advanced cancer, report significant **psychosocial distress**; often **unrecognized** and **untreated**.

Associated with:

- ↓ QoL,
- ↓ Adherence to treatment
- ↓ Prognosis
- ↑ Burden for caregivers and staff
- ↑ At-risk behavior

Memorial Sloan Kettering Cancer Center

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Psychological disorders in cancer patients

Prevalence

More than 30% of cancer patients meet criteria for a psychiatric disorder at some point during their illness*

Depressive Disorders	10% to 25%
Anxiety Disorders	10% to 40%
Adjustment Disorder	20% to 35%
Delirium	20% to 85%

*Cancer diagnosis may exacerbate preexisting psychiatric disorders

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NCCN: Distress During Cancer Care

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Guide 1. Examples of distress symptoms

- Sadness
- Fear, worry, helplessness
- Anger, feeling out of control
- Concerns about illness and treatment
- Worries about paying bills and costs of living
- Questioning your faith, your purpose, the meaning of life
- Pulling away from too many people
- Concerns about taking care of others, such as a child or parent
- Poor sleep, appetite, or concentration
- Depression, anxiety, panic
- Frequent thoughts of illness or death

Some symptoms of distress have other causes, too. An example is poor sleep. Poor sleep may be related to one or more factors, such as pain, heartburn, and medication.

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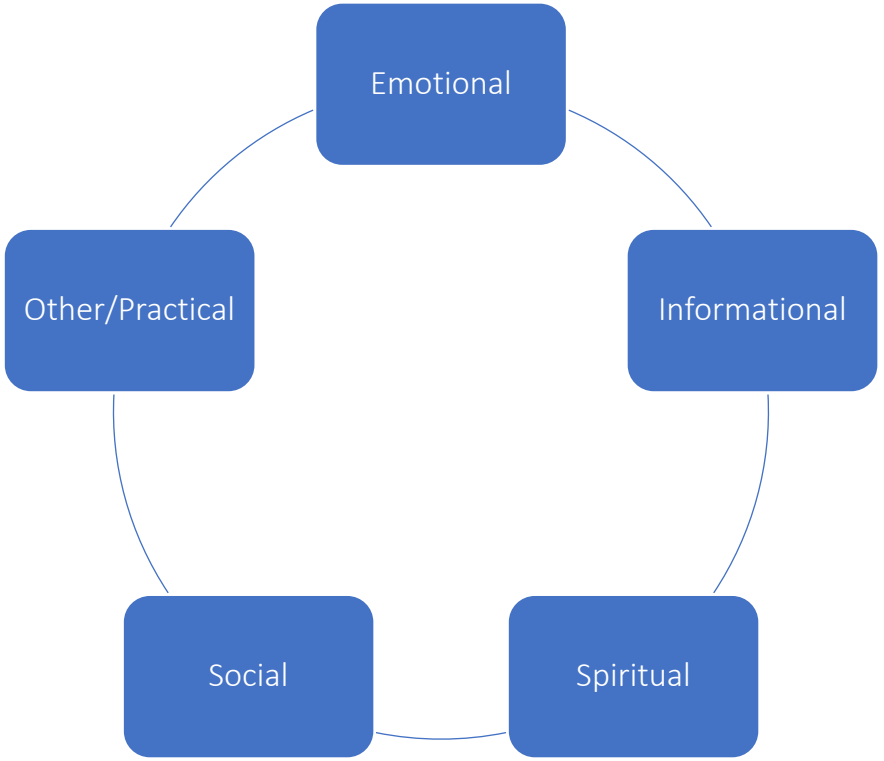
Needs of cancer patients

- Needs can be categorized into:



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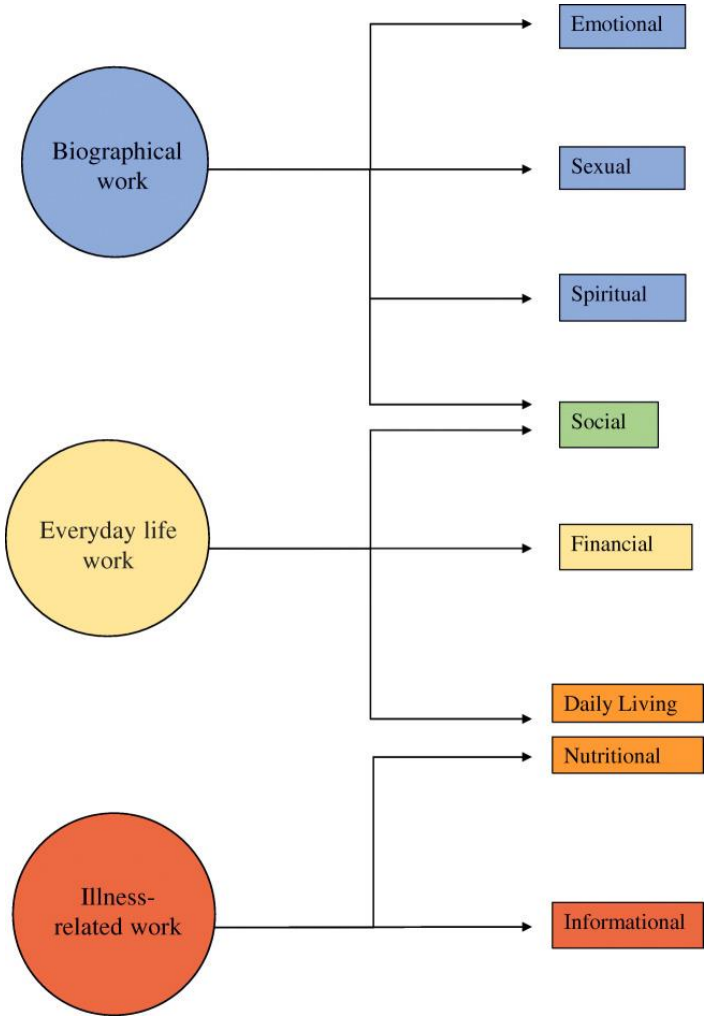
Needs of cancer patients



Webb et al, J Cancer Edu, 2021

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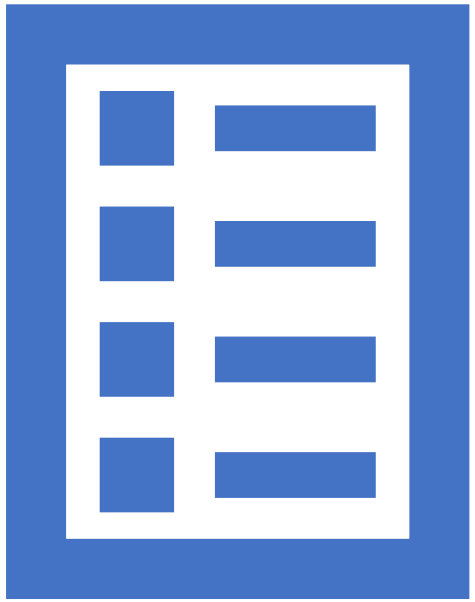
Needs of cancer patients

- Retrospective review of 46 papers
- Grouped common themes of Patient reported needs during cancer



Webb et al, J Cancer Edu, 2021

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Illness related work

- Tasks related to:
- Controlling symptoms
- Monitoring or preventing crises
- Carrying out regimens
- Managing limitations of activity

- **Goal:** Understand illness and treatment
- **High priority:** need for information

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- **Information about:**
  - Treatment: which one, how it works, why selected, effectiveness, pros and cons, side effects, symptom management
  - Diagnosis and prognosis
  - Expectations: illness, treatment, chance of relapse, LOS, when life returns to "normal"
  - Nutritional needs
  - Test results: Quickly and explained

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Everyday Life Work

- Daily tasks that keeps the household going
- Manage illness
- Maintain structure of life pre-diagnosis

- **High priorities:** Concern for family, maintaining relationships, and live a "normal" life

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Everyday Life Work: Examples

- Cope with lack of energy, desire to do things they used to do
- Desire to socialize, and fear of isolation and abandonment
- Maintain a job and effect of cancer on work
- Financial: Stability, support, reliance on others, managing bills, bankruptcy, cost of care, homelessness
- Desire to maintain basic standard of living
- Understand financial systems and resources

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Biographical Work

- The work involved in defining and maintaining identity
- Deals with the emotional impact of cancer

- **High priorities:** Being treated as an individual, be reassured, respected and have feelings acknowledged and dignity preserved

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Biographical Work: Examples

- Feelings of despair, depression, suicidality, anxiety
- Fears of dying and pain
- Managing uncertainty and lack of control
- Sexuality and intimacy issues
- Spiritual needs
- Cultural and religious needs

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Confluence of factors

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The American College of Surgeons Commission on Cancer

- **In 2012, The Commission on Cancer** set a new standard **mandating accredited cancer centers** to have a **psychosocial distress screening program** in place, to **identify** distressed patients, **triage** them to appropriate help, and **follow up** with them

Memorial Sloan Kettering Cancer Center

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Distress Screening Tool

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National Comprehensive Cancer Network®

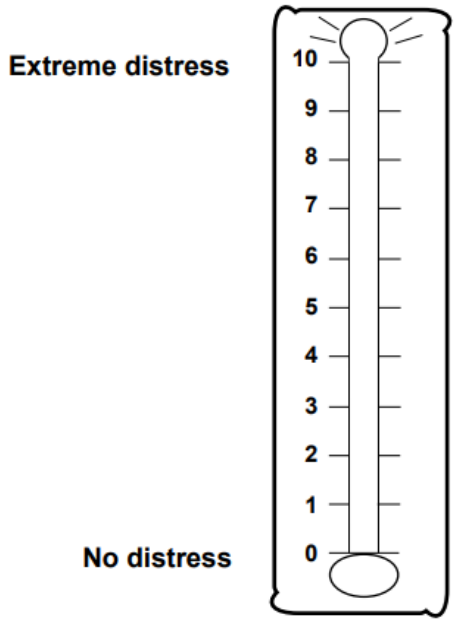
NCCN Guidelines Version 2.2023
Distress Management

NCCN Guidelines Index
Table of Contents
Discussion

NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.



PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical Concerns
- ❑ Pain
- ❑ Sleep
- ❑ Fatigue
- ❑ Tobacco use
- ❑ Substance use
- ❑ Memory or concentration
- ❑ Sexual health
- ❑ Changes in eating
- ❑ Loss or change of physical abilities

Emotional Concerns
- ❑ Worry or anxiety
- ❑ Sadness or depression
- ❑ Loss of interest or enjoyment
- ❑ Grief or loss
- ❑ Fear
- ❑ Loneliness
- ❑ Anger
- ❑ Changes in appearance
- ❑ Feelings of worthlessness or being a burden

Social Concerns
- ❑ Relationship with spouse or partner
- ❑ Relationship with children
- ❑ Relationship with family members
- ❑ Relationship with friends or coworkers
- ❑ Communication with health care team
- ❑ Ability to have children

Practical Concerns
- ❑ Taking care of myself
- ❑ Taking care of others
- ❑ Work
- ❑ School
- ❑ Housing
- ❑ Finances
- ❑ Insurance
- ❑ Transportation
- ❑ Child care
- ❑ Having enough food
- ❑ Access to medicine
- ❑ Treatment decisions

Spiritual or Religious Concerns
- ❑ Sense of meaning or purpose
- ❑ Changes in faith or beliefs
- ❑ Death, dying, or afterlife
- ❑ Conflict between beliefs and cancer treatments
- ❑ Relationship with the sacred
- ❑ Ritual or dietary needs

Other Concerns:

_____

_____

_____

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

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DIS-A

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Psychosocial assessment screening tool

Cancer PROGRAMS
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Figure 2. Patient Health Questionnaire-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? (Use ✓ to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being too fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
FOR OFFICE CODING	____ +	____ +	____ +	____ = Total score: ___

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues, with an educational grant from Pfizer Inc.
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Psychosocial assessment screening tool

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COLUMBIA-SUICIDE SEVERITY RATING SCALE (C-SSRS)

RISK ASSESSMENT VERSION	Past Month	
Ask questions that are in bold and underlined.	**YES**	**NO**
Ask Questions 1 and 2		
1) Wish to be Dead: *Person endorses thoughts about a wish to be dead or not alive anymore, or wish to fall asleep and not wake up.* **Have you wished you were dead or wished you could go to sleep and not wake up?** If yes, please explain:		
2) Non-Specific Active Suicidal Thoughts: *General non-specific thoughts of wanting to end one's life/die by suicide without general thoughts of methods, intent, or plan.* **Have you had any actual thoughts of killing yourself?** If yes, please explain:		
If YES to 2, ask questions 3, 4, 5, and 6. If NO to 2, go directly to question 6.		
3) Active Suicidal Ideation with Any Methods/Means (Not Plan) without Intent to Act: *Person endorses thoughts of suicide and has thought of at least one method. e.g. "I thought about taking an overdose but I never made a specific plan as to when, where or how I would actually do it....and I would never go through with it."* **Have you been thinking about (how) you might do this?** If yes, how? (means) If yes, do you have access to the methods/means?		
4) Active Suicidal Ideation with Some Intent to Act, without Specific Plan: *Active suicidal thoughts of killing oneself and reports having some intent to act on such thoughts. e.g. "I have the thoughts but I definitely will not do anything about them."* **Have you had these thoughts and had some intention of acting on them?** If yes, please explain:		
5) Active Suicidal Ideation with Specific Plan and Intent: *Thoughts of killing oneself with details of plan fully or partially worked out and person has some intent to carry it out.* **Have you started to work out or worked out the details of how to kill yourself?** If yes, do you intend to carry out this plan? If yes, do you have a timeframe (when)? If yes, do you have a location (where)?		
6a) Preparatory Acts or Behavior: *Examples: Collected pills, obtained a gun, gave away valuables, wrote a will or suicide note, took out pills but didn't swallow any, held a gun but changed your mind or it was grabbed from your hand, went to the roof but didn't jump; or actually took pills, tried to shoot yourself, cut yourself, tried to hang yourself, etc.* **Have you done anything, started to do anything, or prepared to do anything to end your life?** If yes, please explain:	**Lifetime**	
6b) If yes, ask: Was this within the past 3 months?	**Past 3 Months**	

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Response Procedure to C-SSRS Screening: **Low Risk** **Moderate Risk** **High Risk**

1) Seek behavioral health counseling services and/or contact crisis line.
2) Seek behavioral health counseling services and/or contact crisis line.
3) Seek behavioral health counseling services, psychiatric services/evaluation, and/or contact crisis line.
4) Seek psychiatric services/evaluation by behavioral health intake/emergency room/EMT.
5) Seek psychiatric services/evaluation by behavioral health intake/emergency room/EMT.
6a) Seek behavioral health counseling services, psychiatric services/evaluation, and/or contact crisis line.
6b) Within 3 months: Seek psychiatric services/evaluation by behavioral health intake/emergency room/EMT.

Any **YES** indicates that the person should seek behavioral health counseling and/or contact crisis lines at: National Suicide Prevention Lifeline (Call or Text) **988**, Behavioral Health Response (BHR) 1-800-811-4760, Provident Crisis Services 314-647-4357, KUTO 1-888-644-5886, Trevor Project (LGBTQ) 1-866-488-7386. However, if the answer to 4, 5 or 6 is **YES**, seek immediate help: contact behavioral health intake, go to the emergency room, or call **911**.

Do Not Leave an "At-Risk" Person Alone. Secure All Means. Remain Calm, Listen, Provide Love & Support.

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What to do?

- **Choose assessment tool**
  - **BB Resource page**
  - **Specific tools for different barriers**
- **REFER TO EXPERTS!**
  - **Chaplains, social workers, psychologists, psychiatrists, navigators, financial counselors, case managers, etc**
- **Create a Community Map**

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WASHINGTON, DC

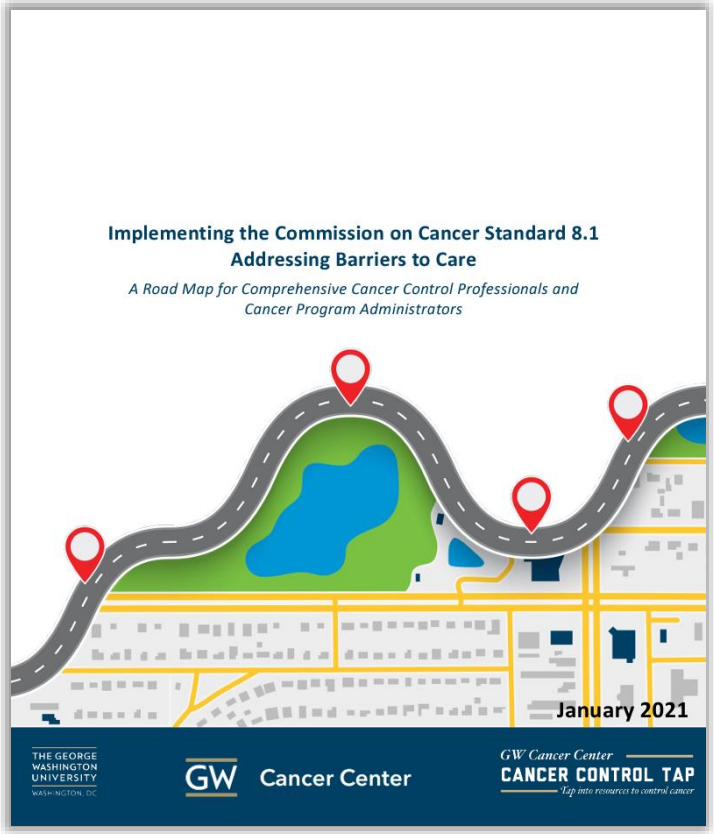
Breaking Barriers QI Project

April 05, 2023

Presented By:
Sarah Kerch & Shayla Scarlett

GW Cancer Center

Presentation Summary



- Background about GW Cancer Center's support to comprehensive cancer control coalitions
- Development of the CoC Standard 8.1 Barriers to Care Toolkit

CDC's National Comprehensive Cancer Control Program

50 states and the District of Columbia

7 U.S. Pacific Island jurisdictions

8 American Indian/Alaska Native tribes and tribal organizations

CDC's National Comprehensive Cancer Control Program

- Establish and convene multisectoral coalitions
- Work with coalition to develop and implement jurisdictional cancer plan

CDC's National Comprehensive Cancer Control Program

50 states and the District of Columbia

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- Establish and convene multisectoral coalitions
- Work with coalition to develop and implement jurisdictional cancer plan

CCC Technical Assistance Provider

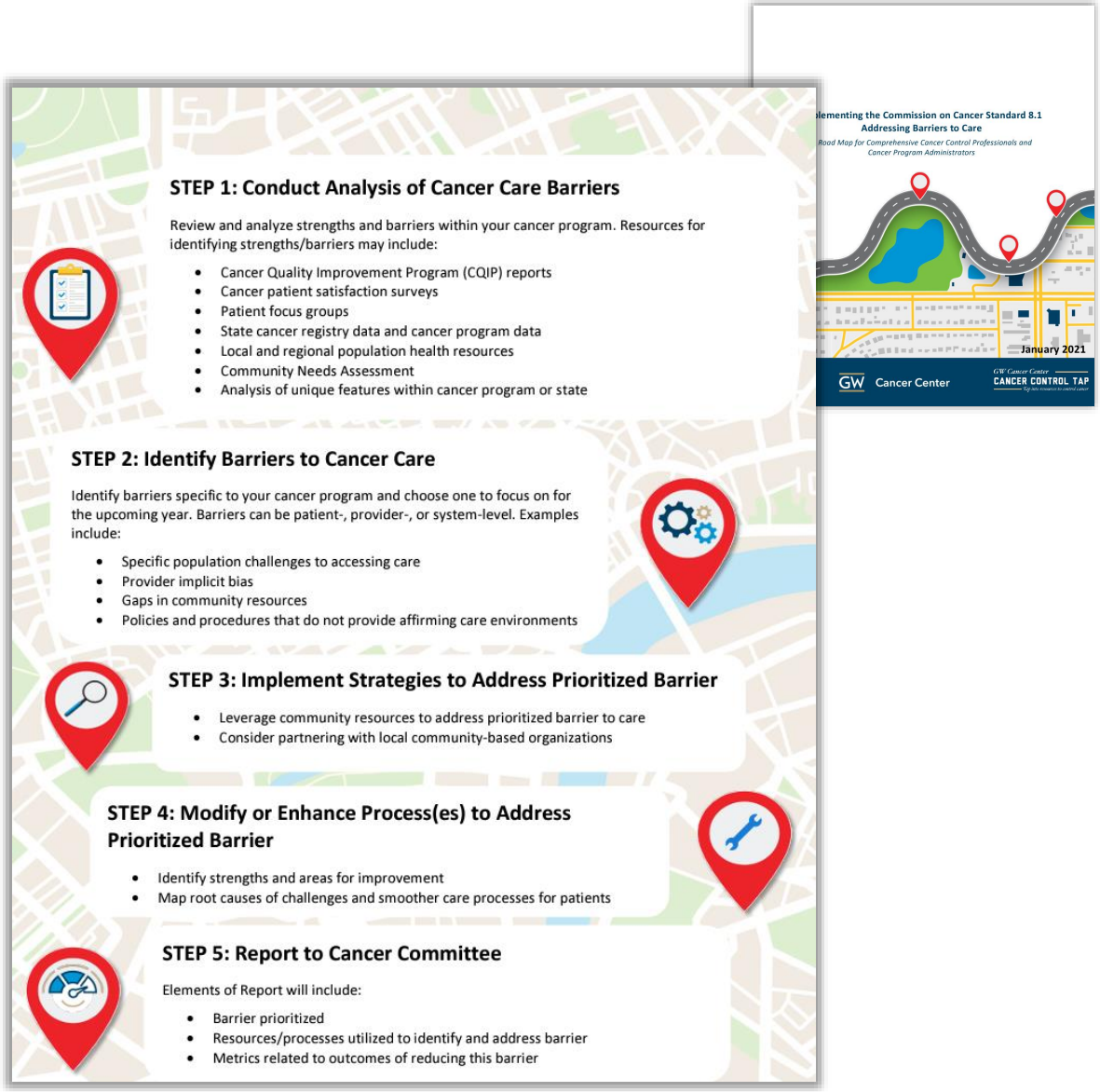
- Funded by CDC since 2013
- One of two technical assistance providers
- One of 17 members of the Comprehensive Cancer Control National Partnership
  - American College of Surgeons is also a national partner

GW Cancer Center
CANCER CONTROL TAP
Tap into resources to control cancer

Comprehensive Cancer Control
Collaborating to Conquer Cancer

CoC Standard 8.1 Road Map

- Developed to support CCC professionals working with cancer programs to:
  - Meet CoC standards
  - Advance cancer plan objectives



A Focus on GW Cancer Control Toolkit

Step 2-Identify Barriers to Care (ACS Adapted Version)

Understanding Barriers to Care

Barriers to care are any sort of obstacle that limits or prevents people from receiving adequate health care

Patient-Centered

Provider-Centered

Health System-Centered

Examples of Patient-Centered Barriers

Logistical

- Transportation issues
- Housing insecurity/transient population

Psychosocial

- Mental health concerns (anxiety, depression)
- Substance use disorders (SUD)
- Social isolation

Economic

- Food insecurity
- Employment
- Lack of insurance or under-insurance
- High co-pays or deductibles
- Prescription medication costs
- Financial and legal issues

Examples of Patient-Centered Barriers

- Patient mistrust or negative perception of health care providers

Cultural and Linguistic

- Low health literacy
- Lack of knowledge about wellness behaviors
- Lack of knowledge about resources or events
- Unclear provider explanations to patients

Communication

Examples of Provider-Centered Barriers

- Perceptions or attitudes, including implicit bias

- Time constraints and demand for health care services

- Administrative barriers

- Provider burnout/ other personal factors

Examples of Health-System Barriers

- Lack of culturally or linguistically competent services
- Systems that perpetuate structural racism

Cultural and Linguistic

- Critical care staff shortages (physicians, nurses, technicians)
- Limited appointment availability, office hours

Institutional

Steps to Address Barriers to Care

1

Know the community you serve **and** key characteristics about the people you serve

Urban vs rural environment	Food access	Internet access	Literacy/ health literacy rates
Race and ethnic identity	Sexual orientation and gender identity	Age demographic breakdown	Languages spoken by patients
Zip codes where your patients reside	% +/- Federal poverty level	Education level	Employment rates
	Insurance breakdown	Substance abuse use	

Steps to Address Barriers to Care

2

Identify the barriers that could most impact the patients in your cancer center

- Review the examples provided under patient, provider, or health-systems barriers
- Consider gathering patient accounts of why appointments were missed in the past in order to prioritize your focus
- Identify potential solutions to address barriers and assess feasibility to implement

Steps to Address Barriers to Care

3

Develop a resource list to address barriers that is regularly reviewed and updated at least every 6 months

GW Cancer Center:

What's Working to Address Barriers

1

Restructured Patient Navigator program in 2022

- Help patients talk with their physician
- Address any issues that might prevent a patient from keeping a medical appointments
- Assist with approvals and referrals required for a patient to receive care
- Help to schedule appointments for screenings, tests, follow up visits and other care recommended by your doctor
- Connect patients with community and supportive care services
- Provide information about the healthcare services recommended by the physician
- Help patients manage financial and insurance issues
- Arrange transportation to and from medical appointments

GW Cancer Center:

What's Working to Address Barriers

2

Integrated social risk factor screening for new patients and patients entering survivorship

EPIC Questions

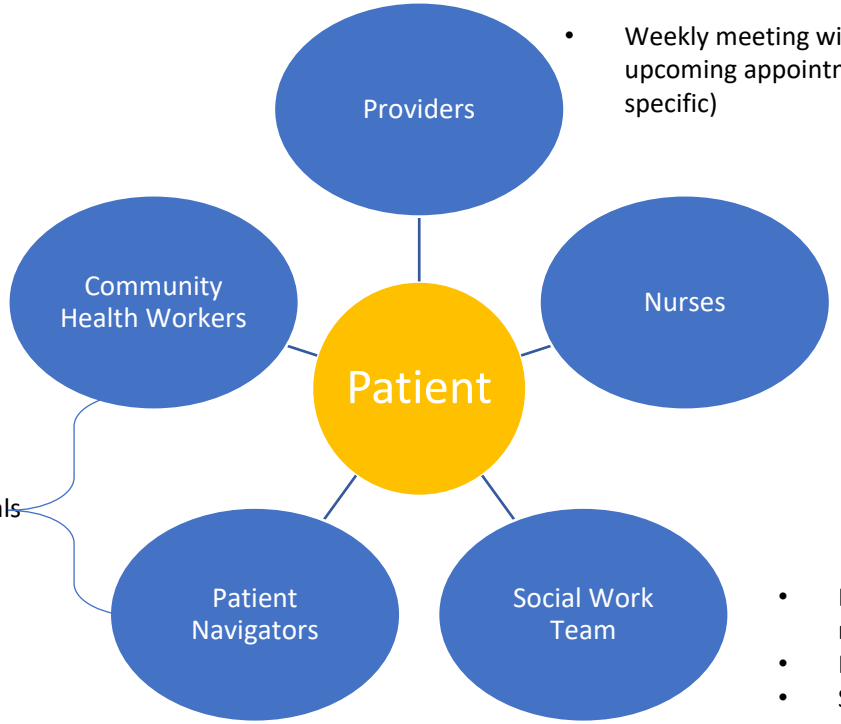
☐ How hard is it for you to pay for the basics like food, housing, medical care, and heating? [FINANCIAL RESOURCE STRAIN]	☐ Very Hard	☐ Hard	☐ Somewhat Hard	☐ Not Very Hard	Not Hard At All	☐ Patient Refused
☐ Within the past 12 months, were you worried that your food would run out before you got the money to buy more? [FOOD INSECURITY]	☐ Never True	☐ Sometimes True	☐ Often True	☐ Patient Refused		
☐ Within the past 12 months, the food you bought just didn't last and you didn't have money to get more? [FOOD INSECURITY]	☐ Never True	☐ Sometimes True	☐ Often True	☐ Patient Refused		
☐ In the past 12 months, has lack of transportation kept you from medical appointments or from getting medications? [TRANSPORTATION]	☐ Yes	☐ No	☐ Patient Refused			
☐ In the past 12 months, has lack of transportation kept you from meetings, work, or from getting things needed for daily living? [TRANSPORTATION]	☐ Yes	☐ No	☐ Patient Refused			
☐ In the last 12 months, was there a time when you did not have a steady place to sleep or slept in a shelter (including now)? [HOUSING INSECURITY]	☐ Yes	☐ No	☐ Patient Refused			
☐ In the last 12 months, was there a time when you were not able to pay the mortgage or rent on time? [HOUSING INSECURITY]	☐ Yes	☐ No	☐ Patient Refused			

GW Cancer Center:

What's Working to Address Barriers

3

Building stronger linkages between members of the patient care team



- Weekly meeting with patient care team to discuss upcoming appointments and patient needs (disease specific)

- Social risk factor screening
- Resource referrals
- Transportation support

- Distress screening and mental health referrals
- Medical-legal partnership
- Support group facilitation

GW Cancer Center:

What's Ongoing/New to Address Barriers

4

Structural training, review, and assessment

- Implicit Bias Training
- Patient Experience Survey (Survivorship)
- Diversity Equity Inclusion Justice (DEIJ) Task Force (Launched Today!)

GW Cancer Center:

Challenges to Address Barriers

Financial resources to address food insecurity and transportation	Challenge
Staffing	
Affordable housing	
Institutional/ individual fundraising	Opportunity
Building relationships with Community Social Workers/ Case Managers Align staffing structure to meet clinical workflow needs	
Advocacy	

GW Cancer Center:

Food for Thought

Have you created a safe space for the patient to feel comfortable to share what they might be experiencing; rapport building is key

Be careful to have resources lined up before you screen patients

Referring a patient to a resource that no longer exists or is complicated to navigate can be counter productive; Have a thorough understanding of how the patient can access the resource, provide support, and regularly monitor the resources being offered

GW Population Observations:

+55 Population

- Rapport building has shown to make a patient feel supported and to open up about needs
- Digital literacy is often low; extra support is needed to navigate some online resources

Quick Resources

Resource Type	Resource
Training	• GW Oncology Patient Navigation Training • Implicit Bias: A Practical Guide for Healthcare Settings
Data	• Barriers to Care ArcGIS • NIH Map Stories • County Health Rankings & Roadmaps • Behavioral Risk Factor Surveillance System • The Surveillance, Epidemiology, and End Results • Census
Community Resources	• Findhelp.org • State sponsored referral programs (e.g. Community Resource Inventory: https://dc.openreferral.org/)

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WASHINGTON, DC

Thank you!

GW Cancer Center

Breaking Barriers: Important Dates

Cancer PROGRAMS
AMERICAN COLLEGE OF SURGEONS

April 15: REDCap survey released to primary contact email

April 30: Pre-survey due, letter of support due, data metrics due

May 12: Next Webinar

June 30: Data Metrics Due; Will include questions about progress of Community Asset Map

- If you need to change your primary contact: email cancerqi@facs.org
- Letter of Support can be emailed directly to cancerqi@facs.org
- Templates for LOS are on the website

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Commission on Cancer
American College of Surgeons

Q and A

Reach out to cancerqi@facs.org