



Oncology Roundtable

# Distress Screening Playbook

# Distress Screening Playbook

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## Introduction

A cancer diagnosis brings physical, emotional, social, psychological, functional, spiritual, and practical consequences into patients' lives. With new Commission on Cancer standards and a shift towards value-driven reimbursement, cancer programs will be increasingly responsible for meeting these diverse needs. To provide sufficient support to their patients, cancer programs need to develop efficient and effective distress management programs. For many programs, connecting patients to the right services in a timely fashion remains a significant challenge. This tool aims to help cancer service line leaders as they implement distress screening and management programs.

To help cancer programs in their efforts, this tool outlines six steps to creating a distress program:

|  |    |
|--|----|
| <b>Step 1:</b> Define your program's capabilities . . . . .              | 3  |
| <b>Step 2:</b> Select a screening tool . . . . .                         | 5  |
| <b>Step 3:</b> Integrate screening into cancer center workflow . . . . . | 7  |
| <b>Step 4:</b> Manage distress interventions . . . . .                   | 8  |
| <b>Step 5:</b> Map process for distress screening. . . . .               | 9  |
| <b>Step 6:</b> Map resources for distress management . . . . .           | 10 |

# Distress Screening Playbook

## Step 1: Define Your Program's Capabilities

### Overview

When establishing distress screening programs, most systems fail to take the time to discuss their priorities for distress management and define a unified vision. To ensure that distress screening is aligned with institutional goals, the first step for cancer programs is to identify all stakeholders that will be involved in distress management. This includes reaching out to institutional resources that can meet patient needs and reduce the burden on cancer resources.

All stakeholders should be involved when discussing the development of a distress management program. Cancer program leaders can use the guides below to organize a planning meeting and to pinpoint internal and external resources that offer support services to cancer patients.

### Invite Relevant Stakeholders to Planning Meeting



Physicians



Nurses



Cancer Program  
Administrators



Patient  
Representative



Clerical Staff



Palliative Care  
Team



Financial Service  
Representatives



Social  
Workers



Substance Use  
Counselors



Pharmacy



IT Staff



Spiritual/Religious  
Service  
Coordinators



Dietitian



Additional  
Ancillary Service  
Providers

### Assess Existing Resources

1. Each representative discusses his/her priorities for distress screening to define one unified vision of what the cancer program should provide to each patient.
2. Each representative states his/her position, capabilities and potential role in screening and management.
3. Team collaboratively identifies hospital-wide resources available to cancer patients.
4. Team collaboratively identifies community resources available to cancer patients.

### Identify Community Resources

In addition to the resources listed on the following page, identify organizations in your town or city that may provide support services for your patients. Consider the following questions:

1. What type of services (i.e., support groups, telephone helpline) do they provide for patients?
2. Do they provide one-on-one support to patients?
3. Do they have an affiliate or community site in your area?
4. Who works for these organizations? Are staff members oncology-trained?
5. Do they offer any support or education for cancer providers?

Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

## Step 1: Define Your Program's Capabilities (cont.)

### Identify Community Resources (cont.)

The table below provides a brief description of a number of national organizations offering free services to patients and providers. Some of the organizations have satellite sites across the country that host in-person events and support groups.

| Organization                            | Services Offered to Patients |                |                      |                                   | Trained Oncology Social Workers on Staff | Free Educational Resources for Providers |
|---|------------------------------|----------------|----------------------|-----------------------------------|--|--|
|   | Education                    | Support Groups | Financial Assistance | Counseling (Virtual or In-Person) |  |  |
| American Cancer Society <sup>1</sup>    | ✓                            | ✓              | ✓                    | ✓                                 |  | ✓  |
| National Cancer Institute               | ✓                            |                |                      | ✓                                 |  | ✓  |
| CancerCare <sup>1</sup>                 | ✓                            | ✓              | ✓                    | ✓                                 | ✓  | ✓  |
| Cancer Support Community <sup>2</sup>   | ✓                            | ✓              | ✓                    | ✓                                 | ✓  | ✓  |
| Association of Community Cancer Centers | ✓                            | ✓              |                      |                                   |  | ✓  |
| LiveStrong                              | ✓                            | ✓              | ✓                    | ✓                                 |  | ✓  |
| Caring4Cancer                           | ✓                            | ✓              | ✓                    |                                   |  | ✓  |
| Cancer Hope Network                     | ✓                            | ✓              |                      | ✓                                 |  |  |
| American Psychosocial Oncology Society  | ✓                            |                |                      | ✓                                 |  | ✓  |

1) Sites in NY, NJ, CT.  
2) Sites nation-wide.

Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

## Step 2: Select a Screening Tool

### Overview

The next challenge for cancer programs is to select a distress screening tool. Most programs fail to consider all possibilities before implementing a screening program. As a team, evaluate which screening tool will best meet your program's and your patients' needs. Consider the following questions when assessing each tool:

- What is feasible with our program's resources?
- What type of support do we want to provide for our patients?
- What IT capabilities do we have?

The table below is a non-comprehensive list of tools commonly used for distress screening.

| Survey Tool   | Length (Average Time to Complete)                                   | Qualitative Description  | Recommended Cut-Off Score <sup>1</sup> | Pricing                |
|---|---|--|--|------------------------|
| <b>NCCN<sup>2</sup> Distress Thermometer (DT) and Problem List (PL)</b> | 1 item on global distress, 34 items on specific needs (2-3 minutes) | <ul style="list-style-type: none"> <li>• DT measures emotional distress with one item on a 0-10 scale</li> <li>• PL assesses psychosocial, practical, and physical symptoms</li> </ul> | ≥4 signals intervention                | Free                   |
| <b>Brief Symptom Inventory (BSI)-18</b>                                 | 18 items (3-5 minutes)  | <ul style="list-style-type: none"> <li>• Global severity index with depression, anxiety, and somatization subscales</li> </ul>   | Men ≥10, women ≥13                     | Available for purchase |
| <b>Edmonton Symptom Assessment Scale (ESAS)</b>                         | 9 items (5 minutes)   | <ul style="list-style-type: none"> <li>• Screens for psychosocial and physical concerns</li> <li>• Most common distress assessment used in Canada</li> </ul>                           | ≥7                                     | Free                   |
| <b>Functional Assessment of Cancer Therapy – General (FACT-G)</b>       | 27 items (5-10 minutes)   | <ul style="list-style-type: none"> <li>• Can be supplemented with tumor- or symptom-specific questionnaires</li> </ul>   | Inverse scoring rubric                 | Free                   |
| <b>General Health Questionnaire (GHQ) -12</b>                           | 12 items (5 minutes)  | <ul style="list-style-type: none"> <li>• Comparable to DT and BSI-18 in detecting distress</li> <li>• Anxiety, depression, fatigue, and social functioning subscales</li> </ul>        | ≥5                                     | Available for purchase |
| <b>Hospital Anxiety and Depression Scale (HADS)</b>                     | 14 items (5-10 minutes)   | <ul style="list-style-type: none"> <li>• Depression and anxiety specific</li> </ul>  | ≥8 anxiety, ≥11 depression subscales   | Available for purchase |
| <b>Kessler (K)-10</b>   | 10 items (2-3 minutes)  | <ul style="list-style-type: none"> <li>• Improves detection in conjunction with DT</li> <li>• Anxiety, depression, fatigue, and agitation subscales</li> </ul>                         | ≥22                                    | Free                   |
| <b>Profile of Mood States (POMS)</b>                                    | 65 items (3-5 minutes)  | <ul style="list-style-type: none"> <li>• Evaluates six mood states: anxiety, fatigue, confusion, depression, anger, and vigor</li> </ul>   | Not available                          | Available for purchase |
| <b>Psychological Distress Inventory (PDI)</b>                           | 13 items (5 minutes)  | <ul style="list-style-type: none"> <li>• Detects anxiety and depression</li> </ul>   | ≥28                                    | Free                   |

1) Patients scoring above the recommended cut-off score may have significant distress, requiring further assessment and intervention by the care team.

2) National Comprehensive Cancer Network.

Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

## Step 2: Select a Screening Tool (cont.)

| Survey Tool   | Length (Average Time to Complete)                    | Qualitative Description   | Recommended Cut-Off Score <sup>1</sup> | Pricing                       |
|---|--|---|--|-------------------------------|
| <b>Patient Health Questionnaire-9 (PHQ-9)</b>                 | 9 items (5 items)                                    | <ul style="list-style-type: none"> <li>Depression subscale of the Patient Health Questionnaire</li> </ul>   | ≥15                                    | Free                          |
| <b>Psychosocial Screen for Cancer (PSSCAN)</b>                | 21 items (5-10 minutes)                              | <ul style="list-style-type: none"> <li>Assesses anxiety, depression, social support, and quality of life</li> </ul>   | ≥8 anxiety, ≥11 depression subscales   | Free                          |
| <b>Questionnaire on Distress in Cancer Patients (QSC-R10)</b> | 10 items (5 minutes)                                 | <ul style="list-style-type: none"> <li>Assesses psychosocial needs and symptom severity</li> </ul>  | ≥14                                    | Free                          |
| <b>Zung Self-Rating Depression Scale</b>                      | 20 items (5-10 minutes)                              | <ul style="list-style-type: none"> <li>Assesses for symptoms of depression</li> </ul>   | ≥50                                    | Free                          |
| <b>Polaris Distress Management</b>                            | Adjustable   | <ul style="list-style-type: none"> <li>Computer adaptive testing</li> <li>Provides patient and provider reports with normalized patient data</li> <li>Assesses physical, emotional, cognitive, and social functioning</li> <li>Patient can choose to receive education or referrals</li> </ul>  | Automated                              | Implementation and yearly fee |
| <b>CancerSupportSource</b>                                    | 25 items (5-10 minutes)                              | <ul style="list-style-type: none"> <li>Provides patient and provider reports</li> <li>Assesses physical, emotional, cognitive, and social functioning</li> </ul>  | Automated                              | Implementation and yearly fee |
| <b>Patient Care Monitor</b>                                   | 80 items (male), 86 items (female) (10-15 minutes)   | <ul style="list-style-type: none"> <li>Assesses physical, emotional, cognitive, and social functioning</li> <li>Provider receives report of patient concerns with potential issues highlighted</li> </ul>   | Automated                              | IT integration fees           |
| <b>SupportScreen</b>  | 53 items (can adjust to institution) (10-15 minutes) | <ul style="list-style-type: none"> <li>Assesses physical, emotional, cognitive, and social functioning</li> <li>Provider receives report of patient concerns</li> <li>Patient can choose to receive education or referrals</li> </ul>   | Automated                              | Implementation and yearly fee |
| <b>NIH PROMIS<sup>®2</sup> Survey Instruments</b>             | 4-7 items per symptom (5-10 minutes)                 | <ul style="list-style-type: none"> <li>Self-reported computer adaptive testing drawn from calibrated item banks</li> <li>Domains for cancer-related depression, anxiety, fatigue, and physical function</li> <li>Assessment Center<sup>SM</sup> enables researchers to create study-specific websites for capturing patient data securely online</li> </ul> | Automated                              | Free                          |

1) Patients scoring above the recommended cut-off score may have significant distress, requiring further assessment and intervention by the care team.

2) Patient Reported Outcomes Measurement Information System.

Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

## Step 3: Integrate Screening into Cancer Center Workflow

### Overview

Once a screening tool has been selected, the next challenge is integrating the screening process into cancer center workflow. Inefficient screening processes will lead to increased staff work and decreased patient capture. The first decision is choosing how to deliver the screening assessment. Many programs currently provide paper-based tools, which require manual scoring and analysis of patient needs. Alternatively, programs may opt to automate screening so that results are instantly linked to the patient record. Automated screening is more efficient, reduces the amount of staff work, and has potential to trigger automatic interventions; however, it requires a significant upfront investment. Decide as a team which delivery mechanism will ultimately help you achieve your goals for distress screening.

| Delivery Mechanism    | Description  | Associated Staff Work | Ease of Patient Use | Technical Support Required |
|-----------------------|--|-----------------------|---------------------|----------------------------|
| <b>Paper-Based</b>    | <ul style="list-style-type: none"> <li>• Tool administered with paper and pencil</li> <li>• Results manually scored, manually entered into patient medical record</li> </ul> | ↑↑↑                   | ↑↑↑                 | ↑                          |
| <b>Tablet-Based</b>   | <ul style="list-style-type: none"> <li>• Tool administered in clinic</li> <li>• Results automatically linked to EMR or patient database</li> </ul>                           | ↑↑                    | ↑↑↑                 | ↑↑                         |
| <b>Patient Portal</b> | <ul style="list-style-type: none"> <li>• Patient can access survey through EMR patient portal</li> <li>• Results automatically integrated into EMR</li> </ul>                | ↑                     | ↑↑                  | ↑↑↑                        |
| <b>EMR Module</b>     | <ul style="list-style-type: none"> <li>• Survey integrated into patient registration process within EMR</li> <li>• Results integrated into medical record</li> </ul>         | ↑↑                    | ↑↑                  | ↑↑                         |

Next, determine how the screening process can best be integrated into cancer center workflow. Consider some of the following questions and potential solutions:

- When is the best time for patients to be screened?
  - Prior to their arrival at the cancer center
  - During registration
  - During nurse intake
  - During physician visit
  - Following the appointment
- Where is the best place for patients to be screened?
  - From their home
  - In the waiting room
  - In the exam room
  - In the resource center
- Who will administer the screening?
  - Registration staff
  - Nurse
  - Social worker
  - Physician

Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

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## Step 4: Manage Distress Interventions

### Overview

One of the biggest challenges for cancer programs is efficiently connecting patients to necessary support services. As a team, you need to decide how patients will be connected to the right services based on the needs identified. Decide the best way to allocate program resources to patients based on the severity of their symptoms. Consider the following:

1. How will scores be analyzed?
  - Registration staff will analyze scores and alert clinician if scores are above threshold
  - Nurses will analyze scores and alert physician if scores are above threshold
  - Physicians will score all screenings and perform more thorough assessment
  - Social workers will analyze all screenings and perform more thorough assessment
  - Automated analysis and alerts integrated into EMR
2. What is an acceptable timeframe for us to follow up with patients?
  - Immediately
  - Within one day
  - Within three days
  - Within one week
3. How can we take the patients' preferences into account when designing interventions?

Cancer programs can lessen the burden of distress management by offering educational support to patients. Given a choice, most low-acuity patients will request education rather than a consult with their care team. Consider the following options:

  - Use patient-administered survey instruments
  - Offer educational resources to all patients
  - Divert educational requests to medical librarian, resource center, or education center
4. Can we make the business case to invest in an automated system?

Although automated systems require significantly more upfront investment than paper-based screening tools, programs should carefully weigh the benefits of automating distress management. Consider the following factors:

  - Staff and clinician time needed to complete paper-based screening and coordinate downstream referrals
  - Potential downstream revenue from support services, such as substance and tobacco use counseling, resulting from automated screening

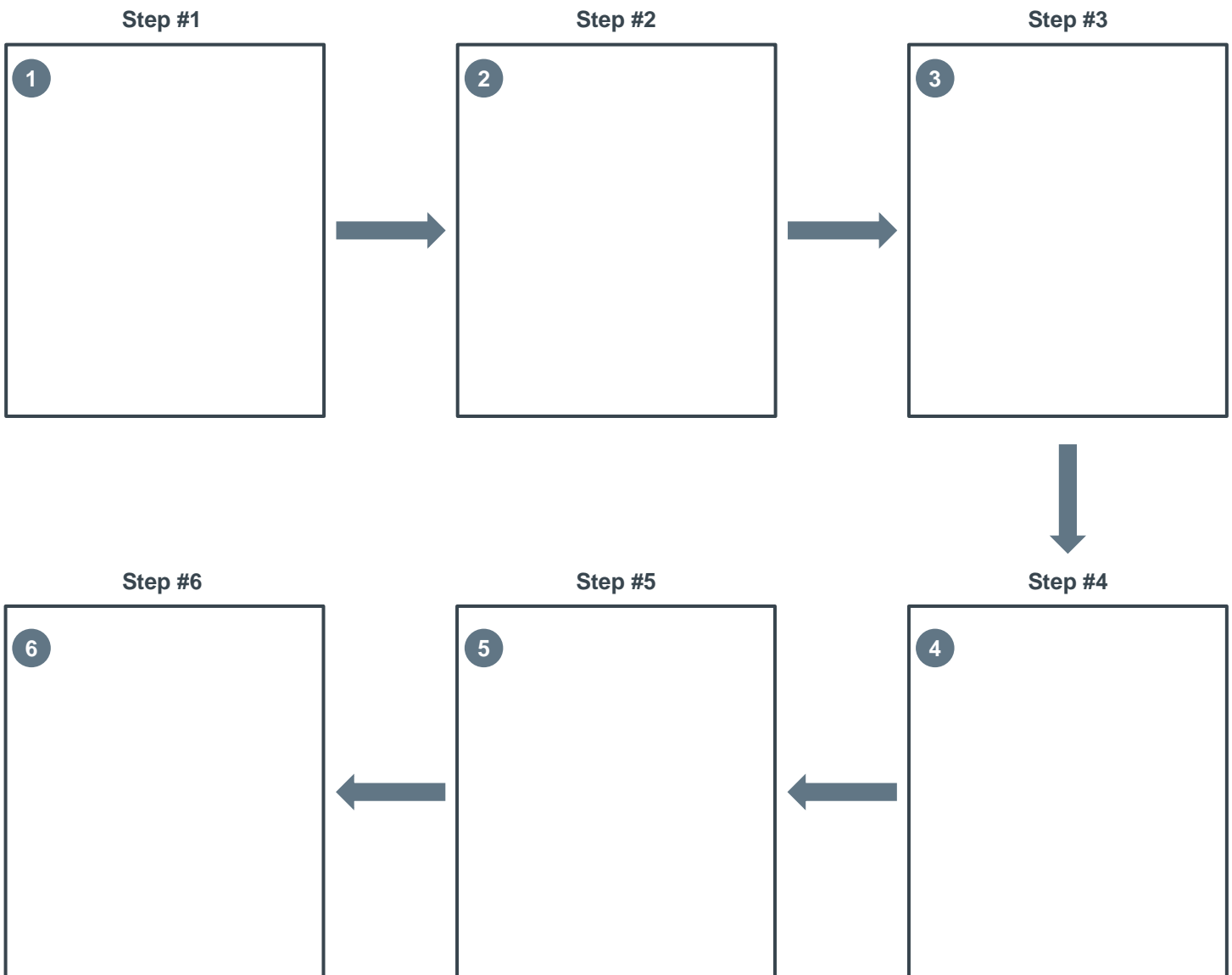


# Distress Screening Playbook

## Step 5: Map Process for Distress Screening

### Overview

The next challenge for the team is to hardwire the distress screening process and assign responsibility for each step. This is critical for creating a unified vision, maximizing screening efficiency, and increasing patient capture. Once the team has defined the screening process, draw out how screening at your institution will look - from distribution of the survey to assessment of patient needs - in the boxes below. Use as many or as few boxes as needed. The more complex the process, the greater the possibility of error, so consider how to consolidate steps if there are more than six. Within each box, write the names of the staff and/or clinicians responsible for each step of the screening process.



Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

## Step 6: Map Resources for Distress Management

### Overview

The final challenge is to define the interventions patients will receive for each specific need. Without a clear distress management plan, patients will experience delays in care or will fail to receive the support they need. For this final step, draw out how your program plans to address the needs uncovered by distress screening. For each box on the left side of the column, identify the need uncovered by screening (depression, fatigue, financial concerns, etc.). For each box on the right, identify resources within the cancer program, institution, and community that will help address each need. On the line beneath each box, indicate the staff, clinician, or team responsible for ensuring that patients are connected to the appropriate support services. Continue onto the following pages as needed.

#### Distress Symptom

#### Downstream Actions



Responsible Parties

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Responsible Parties

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Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

## Step 6: Map Resources for Distress Management (cont.)

**Distress Symptom**

**Downstream Actions**



**Responsible Parties**

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**Responsible Parties**

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**Responsible Parties**

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Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

## Step 6: Map Resources for Distress Management (cont.)

**Distress Symptom**

**Downstream Actions**



**Responsible Parties**

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**Responsible Parties**

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**Responsible Parties**

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Source: Oncology Roundtable interviews and analysis.

# Distress Screening Playbook

## Step 6: Map Resources for Distress Management (cont.)

**Distress Symptom**

**Downstream Actions**



**Responsible Parties**

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**Responsible Parties**

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**Responsible Parties**

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Source: Oncology Roundtable interviews and analysis.