

Select and name the major categories of questions for your tool

1. Pages 3-5 of this packet contain lists of “ingredients” to be included in a patient monitoring tool.
2. The “ingredients” are grouped into three major categories: Body, Mind, and Daily Life.
3. Consider for these categories:
 - a. Are these the best way to group questions for the tool?
 - b. Are these the best titles for the categories?
4. With your team, decide how many categories you will have in your tool and what they will be called.
5. Write the title of each category at the top of a blank Categories & Questions worksheet (pages 5-8 of this packet). If you have more than 4 categories, we have extra sheets.

Select the questions for your tool

1. Pages 3-5 of this packet contain lists of “ingredients” to be included in a patient monitoring tool. Some of these “ingredients” are required, because they were included in the NCCN tool. Others can be adapted for your new tool.
2. With your team, decide which questions to include in your tool.
3. With your team, decide how to word and present each question.
4. With your team, decide on the order in which to ask each question.
5. Write your survey questions onto your blank Categories & Questions worksheets in the appropriate categories. We have extra sheets if you need more space.

Assign “urgency scores” to questions

1. For each of your new survey questions, assign it an “urgency rating.” The urgency rating determines how the provider will respond to a positive response to the question.
 - urgent, act immediately
 - follow up soon/within a day
 - monitor the situation only
2. Write the urgency rating for each question in the appropriate column on your blank Categories & Questions worksheets.
3. This is also a good time to make any final edits to your tool’s major categories and survey questions.

Category: Body (Symptoms, signs...)

Questions: This is a list of possible questions. It is not exhaustive. You may add questions in this category. **Questions in bold are considered to be minimally necessary.** You may change the wording of how the question is asked and introduced.

1. General
 - A. Fevers / Chills / Night Sweats**
 - B. Fatigue (or increased sleepiness)**
 - C. Trouble sleeping**
 - D. Irritability
 - E. **Memory problems** or difficulty concentrating
 - F. **Weight loss** despite adequate calories
 - G. Feeling thirsty despite drinking enough fluids
 - H. Easy bruising or bleeding, skin sores or ulcers
 - I. Skin dry/itchy**
 - J. **Swelling** of the limbs (feet, legs, hands/arms)
 - K. Tingling in hands or feet**
 - L. **Pain** (1-10) (location, quality, onset, duration)
2. ENT
 - A. Headaches
 - B. Blurry vision or vision changes
 - C. Difficulty chewing or eating
 - D. Sores in the mouth or lips**
 - E. Nose dry/congested**
3. Respiratory
 - A. Difficulty breathing**
 - B. Shortness of breath (at rest, on exertion)
 - C. Chest pain
 - D. Cough
 - E. Blood in sputum
4. Heart
 - A. Chest pain
 - B. Palpitations
5. Gastrointestinal
 - A. Nausea/Vomiting**
 - B. Diarrhea**
 - C. Bloody diarrhea or black stools
 - D. Anorexia or increased appetite**
 - E. Constipation**
 - F. Indigestion**
 - G. Increasing abdominal girth
6. Genitourinary
 - A. Increased or decreased urination**
 - B. Pain with urination
 - C. Smelly urine
 - D. Sexual dysfunction**
7. Other somatic complaints by defined patients as important

Category: Mind (Spirit, mood...)

Questions: This is a list of possible questions. It is not exhaustive. You may add questions in this category. **Questions in bold are considered to be minimally necessary.** You may change the wording of how the question is asked, except in the case of questions from validated screening tools, which are underlined below. In that case, however, you may add introductory or explanatory text.

I. [**PHQ2, Depression screening**] Over the last 2 weeks, how often have you been bothered by the following problems

1. Little interest or pleasure in doing things

- Not at all
- Several days
- More than half the days
- Nearly every day

2. Feeling down, depressed or hopeless

- Not at all
- Several days
- More than half the days
- Nearly every day

II. [**GAD2, Anxiety screening**] Over the last 2 weeks, how often have you been bothered by the following problems

1. Feeling nervous, anxious or on edge

- Not at all
- Several days
- More than half the days
- Nearly every day

2. Not being able to stop or control worrying

- Not at all
- Several days
- More than half the days
- Nearly every day

III. [**Loneliness screening**] Over the last 2 weeks, how often have you been bothered by the following

1. Felt that you lack companionship

- Hardly Ever
- Some of the Time
- Often

2. Felt left out

- Hardly Ever
- Some of the Time
- Often

3. Felt isolated from others

- Hardly Ever
- Some of the Time
- Often

IV. Question about spiritual or religious life and/or its impact

Category: Daily life (Living, activities, social, impact on others...)

Questions: This is a list of possible question topic. It is not exhaustive. You may add questions in this category. **Questions in bold are considered to be minimally necessary.** You may change the wording of how the question is asked.

1. Able to carry out basic Activities of Daily Living (ADLs) (**mobility**, laundry, cooking, cleaning, **bathing**, **dressing**, caring for others, **work**, **school**)
2. **Finances** (trouble paying health bills, **health insurance**, rent, food, caregiver, daycare, transportation)
3. **Housing** (access, stability, suitability)
4. **Transportation** (specific problems, vehicle access, gas money, vehicle parts, driver, distance, limitations of medicaid transport)
5. Information (access to information about illness, help with **treatment decisions**, answering questions)
6. Maintaining **family** and social obligations
7. Caregiver burnout and burden
8. Medications and drugs (access to prescribed drugs, taking **unprescribed drugs**, taking home remedies, pain medication abuse, drinking alcohol, using illegal drugs)

Category: _____

	Question text exactly as it will appear on your tool	Urgency rating: urgent; follow up; monitor
1		
2		
3		
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6		
7		
8		
9		
10		

Category: _____

	Question text exactly as it will appear on your tool	Urgency rating: urgent; follow up; monitor
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Category: _____

	Question text exactly as it will appear on your tool	Urgency rating: urgent; follow up; monitor
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Category: _____

	Question text exactly as it will appear on your tool	Urgency rating: urgent; follow up; monitor
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Create the other elements of your monitoring tool

1. Write an introductory text to explain the purpose and meaning of this tool to your users.
2. Create a title for your tool. The metaphor or imagery you choose here may be related to how you communicate results to the patient (e.g. the “Distress Thermometer”)
3. Refine the tone, language, and order of your questions as needed.

Tool Title:

Text:

Prototype a system for calculating the results of the tool

1. Consider the following:
 - a. How are questions in each section weighted or scored?
 - b. What is the relative importance of each question?
 - c. How are questions added up? (By category, overall)
 - d. How should the score be interpreted by providers?
 - e. How should the score be interpreted by patients?
2. Write a description of your scoring method below, and/or make notes on your Categories & Questions sheets to indicate question scoring and weight.

Prototype a way to communicate results to the patient

1. Consider the following:
 - a. After completing the tool, what information does the patient receive?
 - b. In what format is the information shared with the patient?
 - c. Is the score represented numerically, visually, etc.?
 - d. How should the patient interpret the results?
2. Write or sketch a prototype of how the patient will see/understand the results.

Prepare a pitch

You will pitch your new tool to designers and developers who will make it a reality overnight. For each question below, write out the main points. Try to create a pitch that is about **2 minutes** long. A spokesperson for your group will deliver the pitch on camera. Practice your pitch with your group.

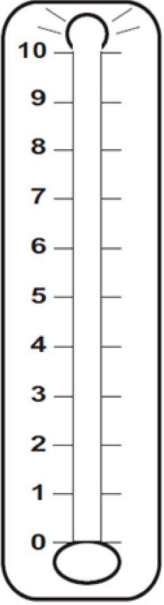
Introduction	<ul style="list-style-type: none">• We are creating a new tool to monitor cancer patients' symptoms• Symptom monitoring is important because it helps patients be more involved in their care, helps providers make more informed decisions, and improves outcomes• Any other information to help people <u>not present today</u> understand what you worked on
Describe your tool. What are its features? How does it work? (1 min.)	
How does your tool specifically address the need you stated?	
What are some questions or uncertainties you have about how it might work?	
What are the next steps for developing this tool?	

NCCN Distress Thermometer

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

Second, please indicate if any of the following has been a problem for you in the past week including today.

Extreme distress! 😬



No distress 😊

Be sure to check YES or NO for each problem

Yes	No	<u>Practical Problems</u>	Yes	No	<u>Physical Problems</u>
<input type="checkbox"/>	<input type="checkbox"/>	Child Care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Substance abuse
<input type="checkbox"/>	<input type="checkbox"/>	Insurance / Financial	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
<input type="checkbox"/>	<input type="checkbox"/>	Work / School	<input type="checkbox"/>	<input type="checkbox"/>	Weight loss/gain
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Eating
			<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
			<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	<u>Family Problems</u>	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
			<input type="checkbox"/>	<input type="checkbox"/>	Fevers
			<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	<u>Emotional Problems</u>	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
<input type="checkbox"/>	<input type="checkbox"/>	<u>Spiritual / Religious Concerns</u>			