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#### **SURVEY INSTRUCTIONS**

Below are questions about your cancer care experience. Think about your entire care experience, unless we state otherwise. For the purpose of this survey, treatment will be defined as any services or support received after your cancer diagnosis. To answer the questions, fill in the bubble below your response.

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How important was the support of the hospital staff (e.g. business services, patient transportation cafeteria) throughout treatment?	Very Important O	Important O	Somewhat Important I		Unimportant O	Don't Know / Not Applicable
2. How important was your family's involvement in your treatment (e.g. the acceptance of family members at appointments, having them included in your care)?	0	0	0	0	0	0
3. How important was having personalized care (e.g. care that matched your learning needs, physical differences, comorbidities, cultural background, future plans, etc.)?	0	0	0	0	0	0
4. How important was understanding your treatment plan?	0	0	0	0	0	0
5. How important was understanding changes in your treatment plan (e.g. changes in medication, delays in treatment)?	0	0	0	0	0	0
6. How important was your relationship with your health care team (e.g. direct care providers)?	O Very	0	O Somewhat	O Of Little	0.	O Don't Know /
7. How concerned were you about the efficient use of time during your treatment?	Concerned	Concerned O	Concerned	Concern	Unconcerned O	Not Applicable
8. How concerned were you about scheduling conflicts between work and hospital visits?	0	0	0	0	0	0
conflicts between work and hospital visits?  SYMPTOM EXPERIENCE  9. How important was knowing about side effects,	Very Important	O	Somewhat Important	Of Little	O	O  Don't Know / Not Applicable
conflicts between work and hospital visits?  SYMPTOM EXPERIENCE  9. How important was knowing about side effects, symptoms, or complications:	Very Important	Important	Somewhat Important	Of Little	Unimportant	Don't Know / Not Applicable
conflicts between work and hospital visits?  SYMPTOM EXPERIENCE  9. How important was knowing about side effects, symptoms, or complications:  a. Before treatment?	Very Important	Important	Somewhat Important	Of Little Importance	Unimportant	Don't Know / Not Applicable
conflicts between work and hospital visits?  SYMPTOM EXPERIENCE  9. How important was knowing about side effects, symptoms, or complications:  a. Before treatment?  b. During treatment?	Very Important	Important  O  O	Somewhat Important	Of Little Importance	Unimportant  O  O	Don't Know / Not Applicable
conflicts between work and hospital visits?  SYMPTOM EXPERIENCE  9. How important was knowing about side effects, symptoms, or complications:  a. Before treatment?	Very Important	Important	Somewhat Important	Of Little Importance	Unimportant	Don't Know / Not Applicable
symptoms, or complications:  a. Before treatment? b. During treatment? c. After treatment? 10. How important was understanding the pain or	Very Important	Important  O  O	Somewhat Important	Of Little Importance	Unimportant  O  O	Don't Know / Not Applicable
SYMPTOM EXPERIENCE  9. How important was knowing about side effects, symptoms, or complications:  a. Before treatment?  b. During treatment?  c. After treatment?  10. How important was understanding the pain or discomfort associated with treatment:	Very Important  O O	Important O O O	Somewhat Important  O  O	Of Little Importance	Unimportant O O O	Don't Know / Not Applicable

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## **SYMPTOM EXPERIENCE** (continued)

11. How concerned were you about changes to your physical health in general?	Very Concerned	Concerned	Somewhat Concerned	Of Little Concern O	Unconcerned O	Don't Know / Not Applicable
12. How concerned were you about any changes in these areas:						
a. Appetite (e.g. what you want to eat)	0	0	0	0	0	0
b. Ability to eat (eating, chewing, swallowing)	0	0	0	0	0	0
c. Ability to taste	0	0	0	0	0	0
d. Nausea / vomiting	0	0	0	0	0	0
e. Bowel movements	0	0	0	0	0	0
f. "Chemo-brain" (e.g. unclear thinking, loss of cognitive function)	0	0	0	0	0	0
g. Memory	0	0	0	0	0	0
h. Fatigue	0	0	0	0	0	0
i. How you look / appearance	0	0	0	0	0	0
j. Fertility	0	0	0	0	0	0
k. Pain	0	0	0	0	0	0
I. Sexual function	0	0	0	0	0	0
m. Sleep	0	0	0	0	0	0
n. Urinary habits	0	0	0	0	0	0
o. Other (please specify):	0	0	0	0	0	0
p. Other:	0	0	0	0	0	0
q. Other:	0	0	0	0	0	0
13. How concerned were you about the following issues related to emotional health:						
<ul> <li>a. A need to have a sense of normalcy (Some patients have stated that cancer can make them feel "not like a normal person".)</li> </ul>	0	0	0	0	0	0
b. Anxiety	0	0	0	0	0	0
c. Depression	0	0	0	0	0	0
<ul> <li>d. Feelings of uncertainty and / or loss of control</li> </ul>	0	0	0	0	0	0
e. Other (please specify):	0	0	0	0	0	0
14. How concerned were you about:						
a. Pain management	0	0	0	0	0	0
b. Returning to pre-cancer health status	0	0	0	0	0	0
c. Adopting a healthier lifestyle	0	0	0	0	0	0
d. Ability to move freely	0	0	0	0	0	0
e. Ability to perform normal work responsibilitie	es O	0	0	0	0	0

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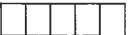
# **SYMPTOM EXPERIENCE** (continued)

15. How concerned were you about getting rid of your cancer?	Very Concerned O	Concerned O	Somewhat Concerned O	Of Little Concern O	Unconcerned O	Don't Know / Not Applicable O
16. How concerned were you about your cancer spreading to other parts of the body (metastasis)?	0	0	0	0	0	0
17. How concerned were you about your cancer coming back?	0	0	0	0	0	0

#### TREATMENT DECISION-MAKING

18. How important was quality of life in making treatment decisions (e.g. ability to participate in daily activities, returning to work)?	Very Important O	Important O	Somewhat Important Ir	Of Little nportance O	Unimportant O	Don't Know / Not Applicable O
19. How important was receiving an explanation of the available options in making treatment decisions?	0	0	0	0	0	0
20. How important was it for health care team members to give consistent information regarding treatment options?	0	0	0	0	0	0
21. How important was the health care team's recommendation in making treatment decisions?	0	0	0	0	0	0
22. How important was reputation in making a decision about treatment (e.g. the reputation of the provider or hospital)?	0	0	0	0	0	0
23. How important was involving you as a partner in making treatment decisions?	0	0	0	0	0	0
24. How important was feeling supported by your health care team when making treatment decisions?	0	0	0	0	0	0
25. How important to you was your emotional / mental state when making treatment decisions:						
a. Before treatment	0	0	0	0	0	0
b. During treatment	0	0	0	0	0	0
c. After treatment	0	0	0	0	0	0

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### **PATIENT & PROVIDER INTERACTIONS**

26. How important was support from your health care team following treatment (e.g. transitioning back to your community provider, where to go for	Very Important O	Important O	Somewhat Important I		Unimportant O	Don't Know / Not Applicable
emergencies)?  27. How important was it for your health care team to recognize possible changes in your priorities or outlook on life as a result of your illness?	0	0	0	0	0	0
28. How important was it for your health care team to recognize any concerns about your cancer returning?	0	0	0	0	0	0
29. How important was it for your health care team to recognize possible concerns about dying from cancer?	0	0	0	0	0	0
30. How important was it for your health care team to recognize any concerns about finances?	0	0	0	0	0	0
31. How important was it for your health care team members to recognize a preference to cope with cancer through faith, religion and / or spirituality?	0	0	0	0	0	0
32. How important was it for your health care team to recognize any anxiety you may have had?	0	0	0	0	0	0
33. How important was it for your health care team members to recognize or be sensitive to any depression you may have been experiencing?	0	0	0	0	0	0
34. How important was it for your health care team members to recognize or be sensitive to any feelings of isolation you may have been experiencing?	0	0	0	0	0	0
35. How important was it for your health care team members to recognize or be sensitive to any need for a sense of hope?	0	0	0	0	0	0
36. How important was it for your health care team members to recognize or be sensitive to any feelings of being a burden to others?	0	0	0	0	0	0
37. Other patients have stated that their cancer experience can make them feel "not like a normal person". How important was it for your health care team to address or understand your need to have a sense of normalcy?	0	0	0	0	0	0

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## **PATIENT & PROVIDER INTERACTIONS (continued)**

38. How important was it for your health care team members to allow time for patient / caregiver questions/concerns?	Very Important O	Important O	Somewhat Important I O		Unimportant O	Don't Know / Not Applicable
39. How important was it for your health care team members to understand concerns about receiving too little information?	0	0	0	0	0	0
40. How important was it for your health care team members to understand concerns about receiving too much information at one time?	0	0	0	0	0	0
41. How important was it for your health care team members to be sensitive to the timing of sharing different types of information?	0	0	0	0	0	0
42. How important was it for your health care team members to check for patient / caregiver understanding?	0	0	0	0	0	0
43. How important was it for different health care team members to give consistent information?	0	0	0	0	0	0
44. How important was it for health care team members to give direct and honest communication (e.g. straightforward, telling it as it is)?	0	0	0	0	0	0

### **RELATIONSHIPS WITH OTHERS**

45. How concerned were you about possible changes in your ability to manage family responsibilities?	Very Concerned O	Concerned O	Somewhat Concerned O	Of Little Concern O	Unconcerned O	Don't Know / Not Applicable O
46. How concerned were you about being a burden on family?	0	0	0	0	0	0
47. How concerned were you about changes in family roles?	0	0	0	0	0	0
48. How concerned were you about changes in relations with supervisors (at work, if applicable)?	0	0	0	0	0	0
49. How concerned were you about other people's perceptions of your health status (e.g. peers, coworkers)?	<b>O</b>	0	0	0	0	0

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REL	<b>ATION</b>	ISHIPS	WITH	<b>OTHERS</b>	(continued)
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50. How important was it for you to have social support from family members?	Very Important O	Important O	Somewhat Important O	Of Little Importance O	Unimportant O	Don't Know / Not Applicable
51. How important was it for you to have social support from friends?	0	0	0	0	0	0
52. How important was it for you to have social support from other current or previous patients?	0	0	0	0	0	0
53. How important was it for you to have social support from religious or faith-based groups?	0	0	0	0	0	0
54. How important was it for you to have access to community assistance and / or services?	0	0	0	0	0	0

#### **SOURCES AND CONTENT OF INFORMATION**

55.	Did you s	search for	health i	information	during your	cancer care	experience?

Q	No	If no, why not?
0	Yes	If yes, which of the following did you look for? (Select all that apply)
		☐ Possible symptoms
		☐ Possible side-effects
		☐ Pain related to disease or treatment
		☐ Information specific to your cancer diagnosis or treatment
		☐ Prognosis

☐ Survival rate

☐ Finances

□ None of the above

□ Cancer reoccurrence

56. How important were the following types of health information **before** treatment?

a. Possible symptoms	Very Important O	Important O	Somewhat Important	Of Little Importance O	Unimportant	Don't Know / Not Applicable
b. Possible side-effects	0	0	0	0	0	0
c. Pain related to disease or treatment	0	0	0	0	0	0
d. Information specific to your cancer diagnosis or treatment	0	0	0	0	0	0
e. Prognosis	0	0	0	0	0	0
f. Finances	0	0	0	0	0	0
g. Cancer reoccurrence	0	0	0	0	0	0
h. Survival rate	0	0	0	0	0	0

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### **SOURCES AND CONTENT OF INFORMATION (continued)**

57. How important were the following types of heart	in intormatio	on <b>auring</b> t	reatment?			
a. Possible symptoms	Very Important O	Important O		Of Little Importance	Unimportant O	Don't Know Not Applicabl
b. Possible side-effects	0	0	0	0	0	0
c. Pain related to disease or treatment	0	0	0	0	0	0
d. Information specific to your cancer diagnosis or treatment	0	0	0	0	0	0
e. Prognosis	0	0	0	0	0	0
f. Finances	0	0	0	0	0	0
g. Cancer reoccurrence	0	0	0	0	0	0
h. Survival rate	0	0	0	0	0	0
58. Rank in order the following resources, with 1 be least important source of information:	eing the mo	st importan	t source of	health info	rmation and 8	3 being the
Family						
Friends						
Health care team						
Online resources						
Other health care teams						
Other patients						
Social networks						
Other resources (please specify):	<u> </u>					
DEMOGRAPHICS						
59. Indicate your cancer site (select only one):						
O Brain						
O Breast						
O Colon						
O Head and Neck O Lung						
O Melanoma						
O Prostate						
O Ovary	Ovary					
O Sarcoma						
O Other (please specify):	O Other (please specify):					

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DEMOGRAPHICS (continued)						
60. How long have you been a patient at MD Anderson?						
O Less Than 1 year						
O 1 – 2 Years						
O 3-5 Years						
O 6 – 10 Years						
O Over 10 Years						
61. Indicate your gender:						
O Female						
O Male						
62. Are you Hispanic or Latino?						
O Yes						
O No						
63. Select one or more of the following races:						
☐ American Indian or Alaska Native						
☐ Asian						
☐ Black or African American						
□ Native Hawaiian or Other Pacific Islander						
☐ White						
Other (please specify):						
64. Indicate your age range:						
O Less Than 18 Years of Age						
O 18 – 30 Years of Age						
O 31 – 45 Years of Age						
O 46 – 60 Years of Age						

	ш	black of Alfican American
		Native Hawaiian or Other Pacific Islander
		White
		Other (please specify):
64.	Indi	cate your age range:
	0	Less Than 18 Years of Age
	0	18 - 30 Years of Age
	0	31 - 45 Years of Age
	0	46 - 60 Years of Age
	0	Over 60 Years of Age
65.	Indi	cate your 5-digit zip code:
66.	Wh	ere did you receive the majority of your care?
	0	Main Campus
	0	Regional Care Centers