

# CEBRE // Field notes

*Patient, family, caregiver interview*

Interview # \_\_\_\_\_

# General information

## Session Information

Interview date \_\_\_\_\_

Interview team \_\_\_\_\_

Participant ID # \_\_\_\_\_

## Participant's Information

Gender ☐ Male ☐ Female ☐ Other

Age \_\_\_\_\_

Medical field or specialty \_\_\_\_\_

Race (Self-identify) \_\_\_\_\_

Highest educational preparation/certification \_\_\_\_\_

*Next: Introduction*

## Section A — Introduction

### Notes

Thank you for agreeing to participate in this interview. We are a research team from the Institute of Design. We are working with the University of Chicago to help think about how we might help support patients being treated with external beam radiation therapy.

Some of us are practicing designers, and our job will be to design a handout or brochure that will help doctors and nurses better communicate important information about the radiation treatment process to patients like *[you/your family member]*, at the initial consultation.

Today, we are hoping to learn more about *[your/your family member's]* experience with radiation therapy and what the process has been like from your perspective. No identifying information will be recorded with your responses. Your responses will be used to guide our team in developing a handout/brochure for patients receiving external beam radiation. We'd like about 45-60 minutes of your time.

*Next: Initial q's and touchpoint intro*

1. To start, can you give us some quick background on your diagnosis and how far along you are in treatment?

2. Touchpoint inventory

We're going to start out with an activity to help us understand your treatment journey so far. As if we were making a timeline of everything that's happened since you were referred to radiation therapy, we're going to ask you to name and explain the largest events or appointments that took place, as well as phases of your treatment.

You can use this sheet to do so (*show timeline*). So, think about your radiation treatment overall and how you would break it down into smaller items. We'll just ask that as you talk about it, you'll use a post-it to mark each event or stage on this sheet. **We'll go through the whole treatment timeline first, and then go back and get more details from you about each point.**

As you go through, we will also ask you to rate your emotions at each stage, using these scales. At each stage, you'll point to one item on each scale to help indicate how you were feeling. (*show emotions in corner of timeline*)

*Next: Touchpoint inventory*

# Section B — Touchpoint inventory/timeline

*Note for primary interviewer: For each touchpoint/point on the timeline, you'll need to probe accordingly based on the touchpoint inventory fields (see notes section on right). A lot of this will come up naturally so you won't have to ask. For the emotions, have them point to scales in front of them for each event/phase. Probe for sensory information - sounds, feelings, temperatures, etc.*

*Note for secondary interviewer: follow along and fill out the touchpoint inventories for each point (including circling emotions that the patients point to)*

3. *[if not answered already]* Were there any surprises along the way?
4. *[if not answered already]* Has anything been particularly challenging?
5. What kinds of questions have you had as you've progressed through your radiation treatment plan?
  - What kinds of topics do you discuss with your care team?
  - Do you feel listened to by your care team?
  - What have you learned from these discussions?

## Notes

Event, stage, or timeframe

# on timeline

What I was **doing**

How I was **feeling** circle one choice from each scale

negative						positive
calm						excited
controlled by something else						in control

What others were **doing**

*Next: Care circle activity - communication and support*

6. Care circle

We would like to do an activity with you that we call the Care Circle. First, we'd like to learn about who you communicate with across the treatment process. We'll put you in the center. Try to think broadly about who you **communicate** most during the treatment process - the circle can include family, physicians/nurses, therapists, and other clinical staff here at the hospital, and anyone else you can think of.

Next, we'll do the same activity but we'd like you to think about the people that provide the most **support** to you during the treatment process. We'll put you in the center again. Try to think broadly about what support and help means to you - again, the circle can include family, physicians/nurses, therapists, other clinical staff, and anyone else you can think of. List the ways in which each person supports you beside or beneath them on the map.

*Note for interviewer: Write the roles that the patient or caregiver lists (unaided) on blue post-it notes. Interviewer also has yellow post-it notes with the following pre-written roles: Medical oncologist, radiation oncologist, primary care provider, social worker, patient service representative, nurse, radiation therapist. If patient does not mention any of these roles, interviewer should ask if they communicate and receive support from these individuals.*

7. Can you put a star next to the people you consider to be the biggest sources of support? Now put a double star next to the one person who is the most important source of help as you go through your radiation treatments.

*Next: Patient Journey: EBRT*

Section D — Patient Journey: EBRT

Notes

*We would like to know more about the medical care you have received so far.*  
**(note: ask what hasn't been covered by touchpoint inventory)**

- 8. When was the topic of external beam radiation therapy first brought up with you? By who?
  
  
  
  
  
  
  
  
  
  
- 9. Do you remember what kinds of questions you had initially about radiation therapy?
  
  
  
  
  
  
  
  
  
  
- 10. On a typical visit to the clinic, who do you interact with? What are their roles?

*Next: Patient Journey: external factors*

## Section D — Patient Journey: external factors

### Notes

11. Are there things you do to help with your recovery in between treatments?

- Are there things you are doing outside of the clinic to take care of yourself?

12. What, if any, expenses have you dealt with related to having radiation treatments?

- Have any unexpected costs or insurance coverage issues come up that you wish you would have known about beforehand?

*Next: Patient education and resources*



## Section E — Patient education and resources

### Notes

13. Do you remember getting any materials to help you learn about radiation therapy? Were they helpful?

- Are there any other resources you use to help you understand and manage your treatment plan? (eg. websites, apps, social media groups, people you ask for advice...)

14. If you experienced or currently experience anxiety about your radiation treatments, are there any tools, techniques or information available to help with that?

15. If you had to describe radiation therapy treatment to a friend, how would you explain it?

*Next: visual styles*

## Section F — Visual styles feedback

### Notes

*We're looking into different formats and styles to explain radiation to patients. We had an artist make these and wanted to get your feedback to help us make them better. (show three styles) There'll be text and speech bubbles that accompany the pictures.*

16. First of all, what do you think about learning about radiation therapy using pictures like these? What works for you? What doesn't? Why?
17. Here we have three different styles of the same story. What do you think of them? Which one works for you? Which one doesn't? Why?
- 17a. What about colors? What is your preference and why?
18. Remembering back to what information you received that explained radiation therapy, how would you compare something like this to the information that you got?

*Next: Wrap-up*

**Section G — Wrap-up**

**Notes**

19. Is there any advice you would give to another patient undergoing radiation therapy who is new to the process? What are the top 3 things you would tell someone who's about to start?

20. Is there anything we didn't ask you today that you wish we would have asked?

**Thank you for your time today and for sharing your experiences  
If you have any questions about the study feel free to contact Dr.  
Golden.**

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