

MBC PATIENT JOURNEY MAPPING EXERCISE v01

MITRE data curation design exercise, planning document, 16.JAN.18

OVERVIEW

This document describes the patient journey mapping exercise that will primarily be conducted during the initial and second interview of the MITRE arm of the data curation study in order to gain a better understanding of the metastatic breast cancer patient experience.

GOALS OF THE JOURNEY MAPPING EXERCISE

- 1. Understand the MBC patient perspective (in relation to both patient experience and data flow through that experience)**
- 2. Learn how patients can best view and interface with SHR data for improved clinical decision-making and cancer research**

Equipment

- Large post-its in at least 2 colors
- Small post-its in at least 3 colors
- Markers
- Large horizontal poster board (24" x 48" or more)
- Pictorial representations of breast cancer terminology and concepts (mammogram, post-surgical, oncologist, caregiver, medication, etc)
- Pictorial representations of each section of the patient record (medications, family history, social history, labs, etc)
- Pre-filled example patient journey map

Method

On-boarding (step 1, 15 minutes) + initial interview (75 minutes)

(First interview)

1. Complete patient consent forms.
2. Introduce the design exercise, the pictorial representations of breast cancer concepts, and answer any questions.
3. Introduce the example pre-filled patient journey map to the patient.
4. Ask the patient to recall their MBC care experience in a stream-of-consciousness fashion. The MITRE team takes notes using the post-its and places them in a pile.
5. As a team with the patient, the notes in the pile begin to be organized on the poster board.
6. On the large poster board, walk through and flesh out the following rows with the help of the patient:
 - a. STEPS: The actual steps of the process, using large post-its. Use 2 colors (one for non-procedure steps, one for procedure steps).
 - b. FEELINGS/EMOTIONS: The negative/positive emotions associated with each step in the process, and why. Use 2 colors (red for negative, green for positive). Think of this as almost 2 sub rows within the feelings/emotions row. The upper row is in relation to the patient themselves. The bottom row is in relation to the patient's family/friends.
 - c. PEOPLE INVOLVED: List of the most important players/people involved at each step. Use small post-its.
 - d. MEDICAL HISTORY: (fill this in the second patient session)
 - e. INFORMATION INTERACTION: Any notes associated with the flow of information. The patients process to educate themselves, coordination across providers, receiving or providing information from providers, etc. Use small post-its.
7. Roughly review the journey map with the patient and rearrange post-its as needed.
8. Work with the patient to identify points in the journey map where solutions/improvements can be injected.
9. Introduce the pictorial representations of the patient record to the patient.
10. Ask the patient to dictate, or rearrange the cards and prioritize them in terms of what information is most important to them.
11. Ask the patient if there are any important sections of patient information they are not seeing, and include them if there are.

12. Ask the patient why they have prioritized the record in their particular way.
13. Explain next steps to the patient:
 - a. Identify provider organizations where medical records are documents and provide patient medical record release authorization forms for medical record collection.
 - b. Schedule second interview.
14. End the first session.
(Between first and second interview)
15. Patient procures copies of their medical records.
16. Reimburse travel/mileage for getting copies of medical records.
(Second interview)
17. Using the medical records, add an extra row to the poster board. MEDICATION HISTORY: Using large post-it notes, write the medical event and its date and arrange it on the poster board. Use the same 2 colors as used in the STEPS row.
(After second interview, for the MITRE team)
18. Generate anonymous identifier for the purpose of study, record mapping of anonymous identifier and patient's PII.

Notes

- The example patient experience map is based off of an account from breastcancer.org:
<http://www.breastcancer.org/community/acknowledging/survivorship/mysunshine48>