

TERMS LIST FOR MBC PATIENT JOURNEY MAPPING v01

MITRE data curation design exercise, 22.JAN.18

OVERVIEW

This document is for use during the patient journey mapping exercise for the MITRE data curation study. It is a list of concepts and terms relevant to a typical metastatic breast cancer (MBC) patient care process. These list of terms will be translated into pictorial representations, and the combination of terms + visuals will allow the participant to more easily remember and share their patient journey and the steps within. This document also includes a list of the names of the various sections of a patient record, to be used to pull out what parts of the record are most important to a patient.

MBC TERMS AND CONCEPTS (58)

Pre-diagnosis [2]

- Genetic testing
- Mammogram screening, diagnostic
- Imaging ultrasound, MRI, CT, x-ray
- Biopsy core needle, FNA, surgical
- Pathology report

Diagnosis [2]

- Non invasive ductal carcinoma in situ, lobular carcinoma in situ
- Invasive invasive ductal carcinoma, invasive lobular carcinoma
- Cancer cell grade grade I, II, III
- Cancer stage stage 0, 1 & 2, 3, 4
- Rate of cell growth ki-67 test, S-phase fraction
- Lymph nodes
- Hormone receptors ER positive/negative, PR positive/negative, HER2 positive/negative
- Cancer genes genetic mutation, genetic abnormality, gene amplification, overexpression
- Type of cancer invasive ductal carcinoma (80% of all), ...
- Second opinion
- Treatment planning

Surgical treatment [2]

- Lumpectomy
- Mastectomy
- Prophylactic mastectomy
- Prophylactic ovary removal
- Lymph node removal
- Breast reconstruction
- Cryotherapy

Non surgical treatment [2]

- Chemotherapy
- Medications [adriamycin](#), [cytoxan](#), [taxotere](#), [methotrexate](#), [fluorouracil](#), [gemzar](#), [ellence](#), [taxol](#)
- Radiation therapy [external](#), [internal](#), [intraoperative](#)
- Hormonal/hormone replacement therapy
- Targeted therapy
- Immunotherapy
- Complementary/alternative/holistic medicine
- Pain treatment

Recovery/support [3]

- Support group
- Faith
- Research study/clinical trials
- Prosthesis
- Follow up care
- Recurrence
- Breast cancer forum

Experience [3]

- Diet & fitness
- Lifestyle
- Relationships
- Family planning
- Pain
- Side effects
- Financial issues [employment](#), [insurance](#)
- Mental/emotional health
- Test results
- Risk
- Community
- Advocacy

People

- Radiologist

- Oncologist
- Physician
- Plastic surgeon
- Pathologist
- Family
- Friends
- Caregiver

HEALTH RECORD SECTIONS (24)

Based on SHR:

- Allergy recent occurrence, irritant, reactions, ...
- Behavior alcohol use, diet followed, exercise hours per week, drug use, sleep quality, ...
- Careplan care team, goal, objective, planned activities, ...
- Condition onset, when clinically recognized, disease progression, ...
- Core (demographic, identification) address, age, name, ...
- Device device used, implanted, vendor model number, ...
- Encounter payment source, referral date, service given, service provider, ...
- Careplan care team, goal, objective, planned activities, ...
- Environment financial situation, home environment risk, household size, income source, annual income, ...
- Family history family member condition, ...
- Financial coverage, insurance member ID
- Immunization immunizations given, immunizations not given, vaccines, ...
- Life history employment, educational attainment, military status, occupation, travel, ...
- Medication medication, dosage, number of refills allowed, amount per dose, administration method, ...
- Oncology TNM stage, breast cancer genetic analysis, tumor dimension size, estrogen receptor status, ...
- Procedure lab procedure performed, specimen collection performed, surgical approach, surgical procedure, ...
- Research sponsor, study arm, principal investigator, ...
- Vital blood pressure, body height, body mass index, body weight, heart rate, respiratory rate, ...

Additional sections [1]:

- Imaging x-ray
- Directive
- Surgical history dates of operations, operative reports, ...
- Pathology biopsy results, ...

- Obstetric history prior pregnancies, complications of prior pregnancies, ...
- Test results blood tests, imaging, pathology, ...

REFERENCES

1. https://en.wikipedia.org/wiki/Medical_record#Contents
2. Grace Kim patient receipt content notes
3. <https://community.breastcancer.org>

