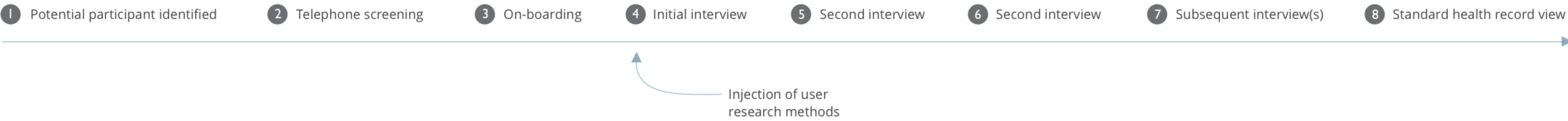# MITRE SHR ONCOLOGY DATA CURATION METHODOLOGY v01

EDWIN CHOI, JUHAN SONIN, 10.JAN.18

*go*invo

This document serves to ensure team understanding of the goals and output of the MITRE data curation study and the methodologies that will be used to generate those findings. It is focused on Phase 1 of the MITRE data curation study.

CURRENT STUDY PROCESS

1 Potential participant identified
2 Telephone screening
3 On-boarding
4 Initial interview
5 Second interview
6 Second interview
7 Subsequent interview(s)
8 Standard health record view

Injection of user research methods

GOALS OF THE STUDY

1 **LEARN HOW PATIENTS CAN BEST VIEW AND INTERFACE WITH SHR DATA FOR IMPROVED CLINICAL DECISION-MAKING AND CANCER RESEARCH.**

Identify how and when the patient can most easily provide data that is difficult for the clinician to obtain and capture.

An SHR that contains the vital elements of a patient's medical history in one single, high-quality health record. We will collect longitudinal data and organize it into a high quality medical record.

Generate an SHR prototype for metastatic breast cancer patients.

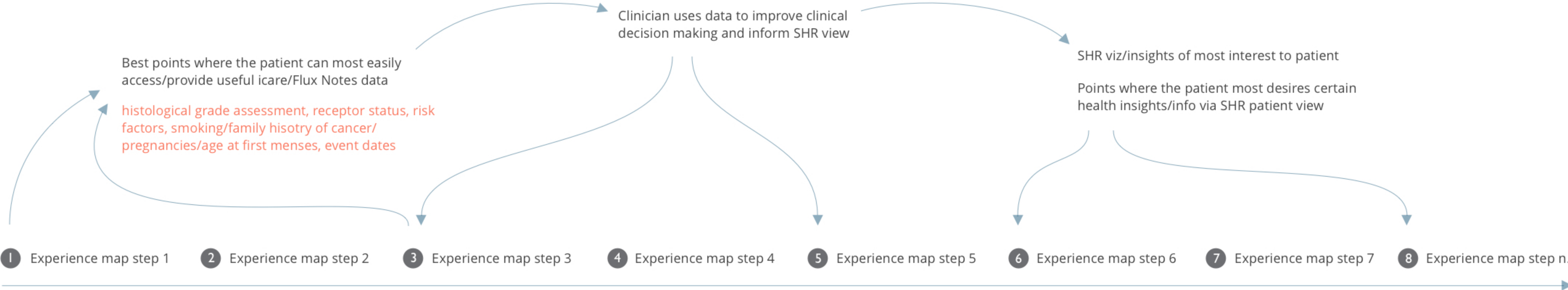2 **UNDERSTAND THE METASTATIC BREAST CANCER PATIENT EXPERIENCE**

Using proven design methods we will generate a metastatic breast cancer care patient journey map (linked with the flow of icare/Flux Notes data).

POSSIBLE EXERCISES TO EXTRACT INSIGHTS

QUESTION AND ANSWER MOTIVATIONAL INTERVIEWING

VISUALIZATIONS TO UNDERSTAND THE PATIENT EXPERIENCE AND SHR VIEW

CONTEXTUAL INQUIRY...

JOURNEY MAPPING SYNTHESIS

EXAMPLE OUTPUT FROM INSIGHTS GAINED VIA MITRE CURATION STUDY
PATIENT EXPERIENCE MAP

Best points where the patient can most easily access/provide useful icare/Flux Notes data

histological grade assessment, receptor status, risk factors, smoking/family hisotry of cancer/ pregnancies/age at first menses, event dates

Clinician uses data to improve clinical decision making and inform SHR view

SHR viz/insights of most interest to patient

Points where the patient most desires certain health insights/info via SHR patient view

1 Experience map step 1
2 Experience map step 2
3 Experience map step 3
4 Experience map step 4
5 Experience map step 5
6 Experience map step 6
7 Experience map step 7
8 Experience map step n...

GUIDELINES FOR DRIVING MBC PATIENT SERVICES