

Perspectives of Cancer Survivors on their Transition from Active to Follow-Up Cancer Care

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The Research Process



Define the
Research
Problem

Literature
Review

Hypothesis
Formulation

Preparing
Study
Design

Administer
Instruments

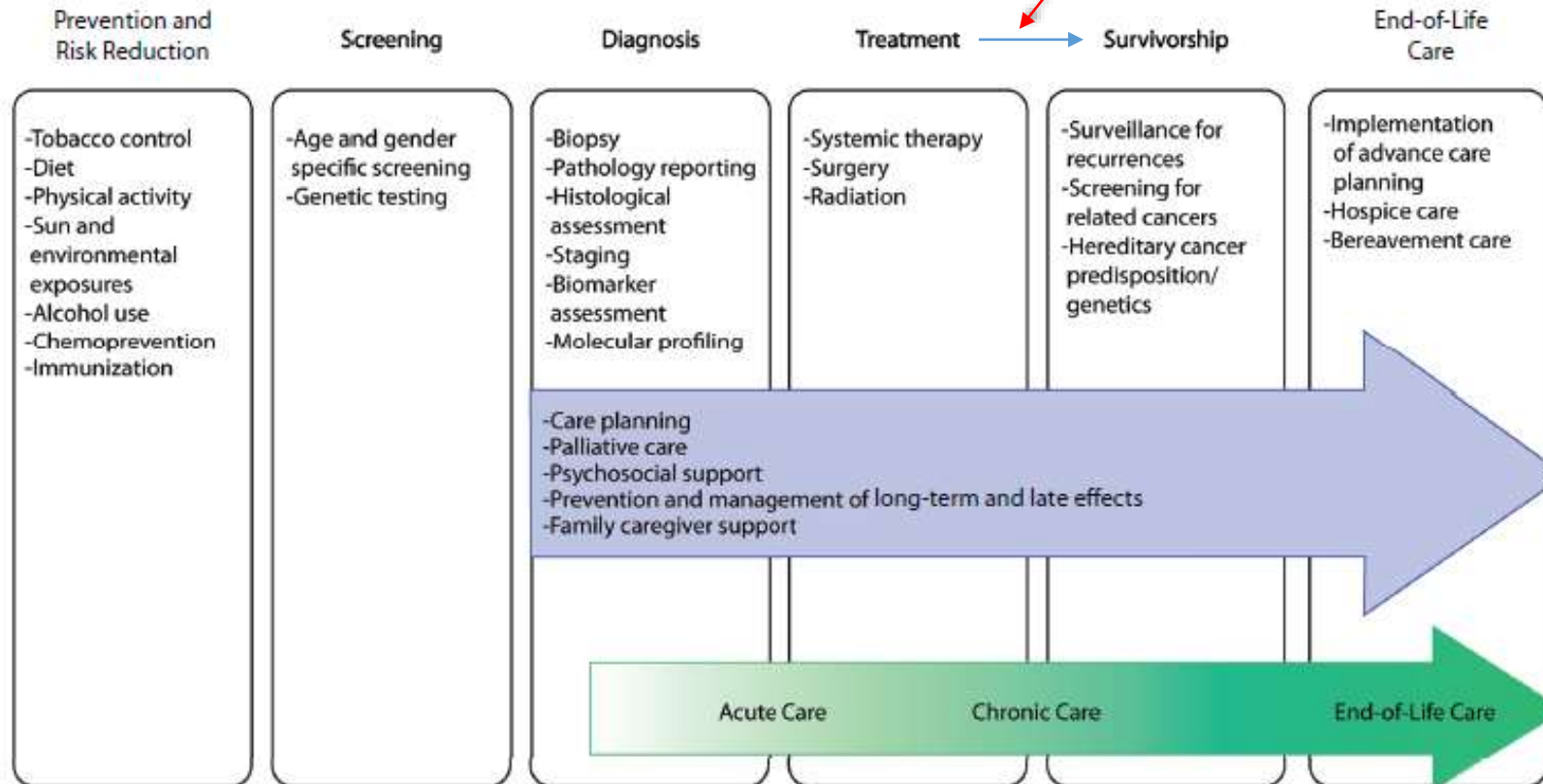
Data
Collection

Data
Analysis

The Problem

- Patients are often lost in the transition from active treatment with their oncologist to follow-up cancer care with their primary care physician.
- This means their survivorship care needs may be inadequately met.¹⁴
 - **Prevention** of new and recurrent cancers
 - **Surveillance** for recurrence of original or new cancers
 - **Interventions** for effects secondary to cancer and cancer treatment
 - **Coordination** between specialists and PCPs

The Cancer Care Continuum



The Cancer Care Continuum. Figure adapted from the Institute of Medicine. From Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population, 2013 by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC, USA

Background

- Number of cancer survivors is rapidly rising in the United States¹³
- Information about follow-up care for patients is abundant^{3,4}
- Clinical practice reflects variation across care guidelines¹
- Shortage of oncologists and PCPs⁵
- Oncologists lack time and resources⁵⁻¹²
- New and significant demands on PCPs⁵⁻¹²
- Lack of partnership between oncologists and PCPs
 - Lack of provider role clarity, information exchange, adequate compensation²

Significance

- Patients are often left out of the equation in cancer care continuum studies
 - Need for focus on patient satisfaction, knowledge of disease, and subsequent patient behavior following education¹
- Lack of studies investigating survivorship care as a whole¹
 - Uptake and duration
 - Quality of Care
 - Resource Utilization
 - Cost
 - Outcomes
- Information about patient experiences and knowledge is essential in closing the gaps in caring for cancer survivors to increase quantity and quality of life

The Research Process



Literature Review

- 36 Publications Reviewed
- 13 Primary Research examples
 - Research question studied?
 - Suggestions for further research?
- 18 Secondary Research examples
 - 8 systematic reviews
 - Research questions studied?
 - Summary of past research?
 - Areas in need of further study?
- 5 Non-Research examples
 - Any useful information was extracted

Most Informative Articles

1. Adult Cancer Survivors Discuss Follow-Up in Primary Care: ‘Not What I Want, But Maybe What I Need’
 - SV Hudson, et al. *Annals of Family Medicine* 2012
 - Qualitative, semi-structured, in-depth interviews
 - Purposive sample of 42 early-stage breast and prostate cancer survivors
 - Stratified by age, race, and length of time from and location of cancer treatment
 - Survivors at least 2 years beyond completion of active cancer treatment
 - Results:
 - 52% preferred to receive follow-up care from their cancer specialists
 - Only 38% believed there was a role for PCPs in cancer follow-up care
 - Performing routine cancer screening tests
 - Supplementing cancer and cancer-related specialist care
 - Providing follow-up medical care when “enough time has passed”

Most Informative Articles

2. Health care needs of cancer survivors in general practice: a systematic review

- RA Hoekstra, et al. *BMC Family Practice* 2014
- Qualitative or quantitative studies
- Sample: survivors of any cancer type, free of active disease, no longer receiving active treatment
- 15 studies included – 12 qualitative
- Results
 - Most mentioned general practice needs were psychosocial needs
 - Need for help with medical issues
 - Need for information on cancer, recovery, late treatment effects and adjusting to life after treatment

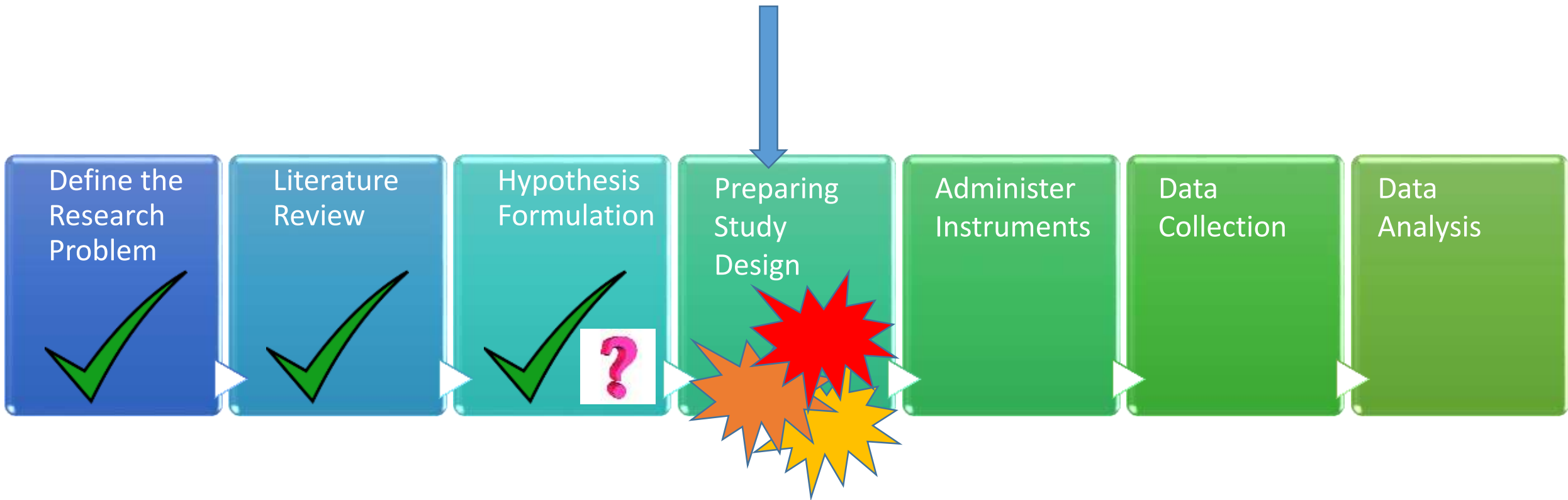
The Research Process



Hypotheses

- In the transition from active treatment to on-going care with a PCP, cancer survivor patients experience poor communication and coordination between their oncology and primary care providers.
- ↓
- Poor communication and coordination exists between cancer survivor patients, their oncologist(s), and their primary care providers during their transition from active treatment to follow-up care with a PCP.

The Research Process



Preparing Research Design

- Develop purpose of the study
- Complete implementation steps

Purpose of Study

1. Better understand the cancer survivor **experiences and perceptions** regarding their follow-up cancer care.
 - Type of doctor that fills “follow-up care” provider role
 - Extent of provider-patient communication
 - Provider responsibility for key aspects of follow-up cancer care
 - Confidence in provider knowledge and skills
 - Follow-up cancer care satisfaction
 - Patterns of seeking follow-up cancer care
 - Preference for type of provider for follow-up care and for how long
 - Rating of provider-provider follow-up cancer care coordination

This study is complementary to a Stephenson Cancer Center pilot study:

Oncology and Primary Care Coordination: Perspectives of Care Providers, Kathleen Dwyer, PI

Implementation Steps

- Finalize Protocol
 - Study Sample
 - Methods
- Finalize Instruments
 - Beta testing
- Consent Forms
- IRB Application
- FMC clinician commitment
- EMR review, cancer codes
- Ask clinician if selected patients fit criteria

Study Sample

- 25 cancer-diagnosed individuals who are active patients at the OUHSC Family Medicine Clinics (FMC)
 - ICD-9 Diagnosis codes: 140.0-208.9, for the prior five years
 - Agreement from specific FMC clinicians to approach eligible patients
 - “Pull” 2 week appointment schedules for those clinicians agreeing to participate
- Check with participating FMC clinicians if identified patients meet inclusion criteria
 - Completed treatment at least 1 year prior to study participation

Methods

- **Data Collection**

- **Closed-ended paper survey administered in person**

- Administered at time of scheduled FMC doctor's appointment
 - Contact patients in advance prior to their participation in study
 - Obtain consent, administer survey at time of appointment
 - Incentive provided following completion of survey (\$25 gift card)

- **Semi-structured interview administered by phone**

- Conducted with survey participants who volunteer
 - 6 questions
 - Aimed at supplementing the quantitative data obtained from the survey

Instruments

- Paper Survey
 1. Survivor Experiences, Perceptions & Preferences:
 - 14 topic questions composed of 57 total items
 - specific attention on the interface between the oncology care delivery system and the primary care delivery system
 2. Survivor Profile:
 - 10 demographic items
 - 8 items about patient's cancer and health status
- Semi-structured phone interview

Beta Testing

- 3-5 cancer survivors will complete the survey
 - Clarity
 - Relevance
 - Important issues included?
 - Additions?
 - Deletions?
 - Length of time to complete the survey
- Beta testing will also be done with the phone interview questions
- Spoke with 2 participants this morning

Implementation Steps

- Finalize Protocol ✓
 - Study Sample
 - Methods
- Finalize Instruments ✓
 - Beta testing
- Consent Forms ✓
- IRB Application
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- EMR review, cancer codes
- Ask clinician if selected patients fit criteria

The Research Process



Supplemental Experiences

Supplemental Experiences

- Shadowing at the Supportive Care Clinic
- Attending a cancer support group meeting
- Meeting with clinicians to discuss patient transition and instruments

Supportive Care Clinic

- Stephenson Cancer Center
 - 2nd floor – next to Breast Cancers Clinic
- Dr. Steve Orwig

Cancer Support Group Meeting

- Project31
 - Breast cancer support group
 - Sarah McLean
- Dr. Theobald

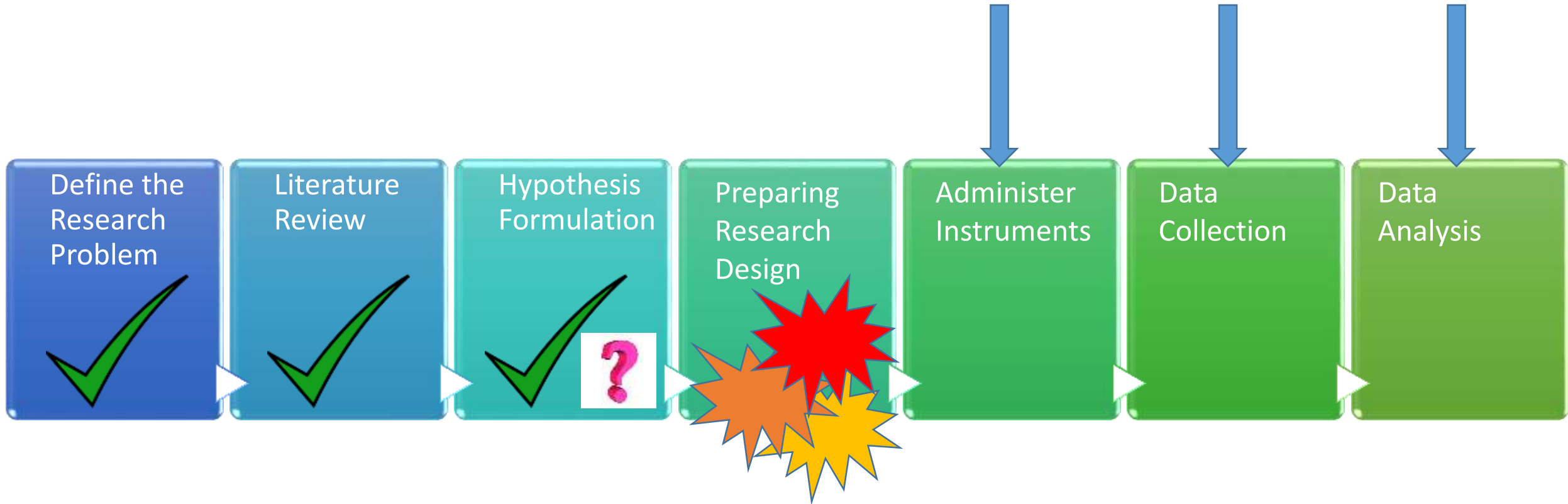
Clinician Meetings

- Dr. Doescher
- Dr. Tietze
- Dr. Salinas

Tell us a little about the cancer patients you have in your care.
What do your cancer patients see you for? What do they say?
What would you have had in place to facilitate the transition process?
What do you think patients want in their transition?
How often would you say you have contact with oncologists regarding your patients?
Where are your patients referred for psychosocial support?
What would you like to know from patients making the transition?

- Common themes:
 - Large variety of cancer patients, Dr. Tietze mostly breast cancer patients
 - Patients are usually seen for other comorbidities and diseases
 - Summary letter from oncologists would greatly help the transition
 - Overall, patients want to feel better and to have someone LISTEN
 - Very little to no communication with oncologists
 - Patients often do not receive the psychosocial support they need

What's Left?



Planned Analysis

- Descriptive statistics (Initially)
 - Including comparison of descriptive stat results for comparable questions across patient, PCP and oncology specialist surveys
- Further on with larger sample size:
 - Likely analysis via Chi-square statistics to assess bivariate associations between key variables
 - Likely multivariate regression analysis with those variables found to be statistically significant in bivariate analyses

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- Dr. Salinas
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- Cara Vaught
- Beta Testing participants

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Questions?