

## Reveal an Urgent Need to Name and Explain the Concept

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### Background

- Trials involving reductions in cancer treatment, particularly chemotherapy, are a growing trend
- The hope is that eliminating/reducing drug(s) will reduce toxicity burden and increase QOL without increasing recurrence or death
- Large well-designed clinical trials are needed to ensure the hope becomes a reality

### Objective

- Understand consumer perceptions to inform design and communications that enhance accrual

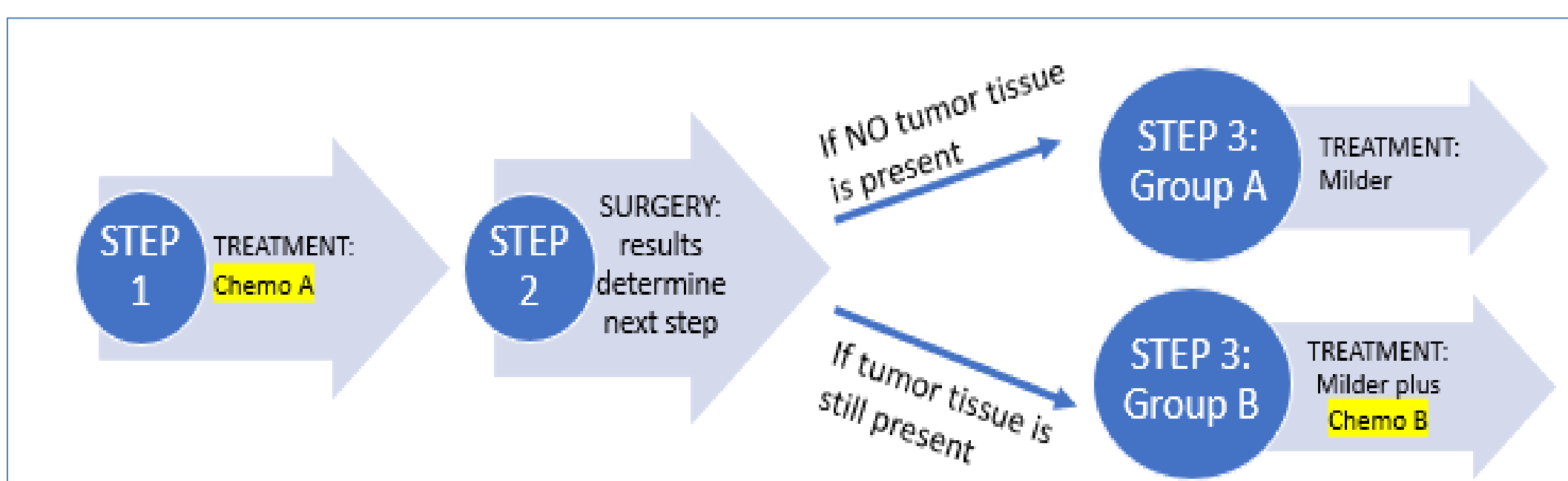
### Methodology

Qualitative study including 5 online focus groups, in April/May 2020 (after COVID pandemic began)

- 2 with patients to draw on experience; identified and recruited via Living Beyond Breast Cancer (diagnosed with HER2+ breast cancer 3-5 years ago)
- 3 with consumers who had never had cancer, identified via nationwide market research panel
  - Provide “cancer-naïve” perspective that may more closely match that of newly diagnosed patients
  - Inform understanding of public opinion, potentially a key in acceptance of reduced treatment

### Topics and Discussion Flow

- Used a current study (EA-1181) as a basis to create a simplified schematic; asked about questions/interest, motivations, concerns, and descriptive language



*Patients and consumers expressed questions, motivations, and concerns about a trial that included possible reduction in treatment*

## motivations

- **Avoiding some chemotherapy (includes avoiding side effects, as well as reducing cost and shortening recovery time)**
- **Taking only what is needed**

## questions

- **Reasoning and rationale**
- **Oncologist recommendation**

## concerns

- **Timeline, particularly the possibility of much longer duration of chemotherapy**
- **Fear of unknown and of “doing less”**
- **Cost**

*Patients and consumers also had some strong reactions to language*

## language

- **“De-escalation” was universally disliked**
- **Positive reactions to terms aligned to motivations: lighter, milder, more manageable, less invasive, minimal**

### Results

1. Initial reactions were not particularly positive or negative; Questions are to be expected and oncologist recommendation is essential
  - Reasoning and rationale
  - Timeline
  - Details of each part of therapy, particularly what might be avoided
2. Motivations aligned with trial goals
  - Avoiding some chemotherapy
  - Taking only what is needed
3. Concerns were significant
  - Lengthening duration of treatment: Participants perceived that the path with additional chemotherapy would translate to more months of treatment, a significant barrier to interest
  - Fear: The results are unknown; some need to feel they have done “everything” to avoid decision regret
  - Cost: Potential for more visits and time out of work represents significant cost, even if treatment covered
4. Language reactions and discussion favored focus on the positive aspects of reduced treatment
  - Positive reactions to: lighter, milder, more manageable, less invasive, minimal
  - Strong negative reactions to de-escalation (military connotations)
  - Some negative reactions to toxicity (unfamiliar and frightening)

### Discussion

- Patient reactions suggest communication approaches are needed to enhance accrual
  - Find a term to replace de-escalation
  - Employ appropriate descriptions of possible upsides: take only what is needed; possibly reduce side effects, costs, and time burden
  - Address concerns to the degree possible:
    - Can duration issue be mitigated if longer path is seen as “only traveled if needed?”
    - Can fears be addressed with open conversation and psycho-social support?
- Perhaps fear of “taking less” can be reduced by addressing “more is always better” attitudes/norms at broader/societal level
- Oncologist recommendation is key; therefore, they need to be equipped with language and tools to provide rationale, address questions, and communicate as effectively as possible

### Future Directions

- Conduct a survey with patients and consumers to quantify these small sample findings
- Develop descriptions of trials that employ patient-centered language
- Provide oncologists with language and tools

### Limitations

- Focused on chemotherapy, not other modalities
- Patients drawn from LBBC lists may not be reflective of general patient population; Consumers willing to participate in a focus group may be biased
- Focus group format provides qualitative input and participants may be influenced by one another; analysis involved simple extraction of themes by research team
- Total sample included only 30 people