

# Development of the Fear of Cancer Recurrence Therapy Intervention for Adolescent and Early Young Adult Survivors of Childhood Cancer (FORT-AeYA): Adaptation and Usability Study

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## Goal

To develop a developmentally appropriate and community-relevant intervention to address fear of cancer recurrence (FCR) experienced by adolescent and early young adult survivors of childhood cancer

## Background

- Fear of cancer recurrence (FCR) is the persistent worry that cancer will return, progress, or lead to new cancers<sup>1</sup>
- Up to 90% of pediatric survivors report some level of FCR<sup>2</sup>
  - An estimated 1 in 3 experience clinically significant FCR<sup>3</sup>
- For survivors of childhood cancer, FCR may first emerge and intensify in adolescence and early young adulthood as survivors take on greater responsibility for their healthcare, begin planning for the future, and navigate late effects<sup>4</sup>
- No interventions currently target youth or FCR experienced by survivors of childhood cancer
- The Fear of Recurrence Therapy (FORT) is a six-week, group-based intervention for adults which has demonstrated strong feasibility, acceptability, and efficacy, including significant improvements in FCR and quality of life<sup>5</sup>

## Objectives

- Adapt the Fear of Recurrence Therapy (FORT) manual for adolescents and early young adults (ages 13–25; FORT-AeYA) through co-design with persons with lived experience
- Redesign intervention materials to improve engagement, accessibility, and developmental fit
- Conduct a usability study with end-users to identify additional refinements prior to pilot testing

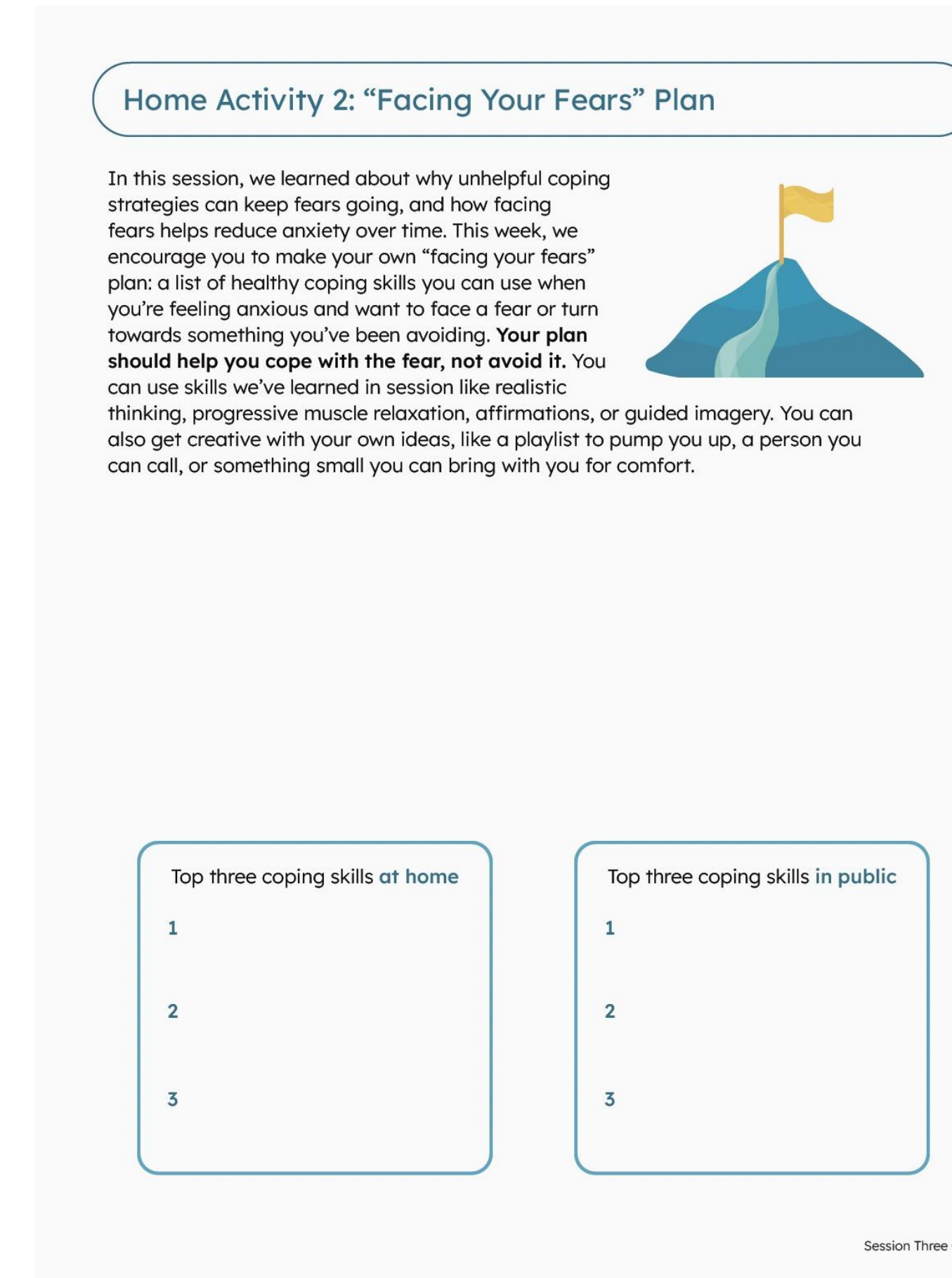
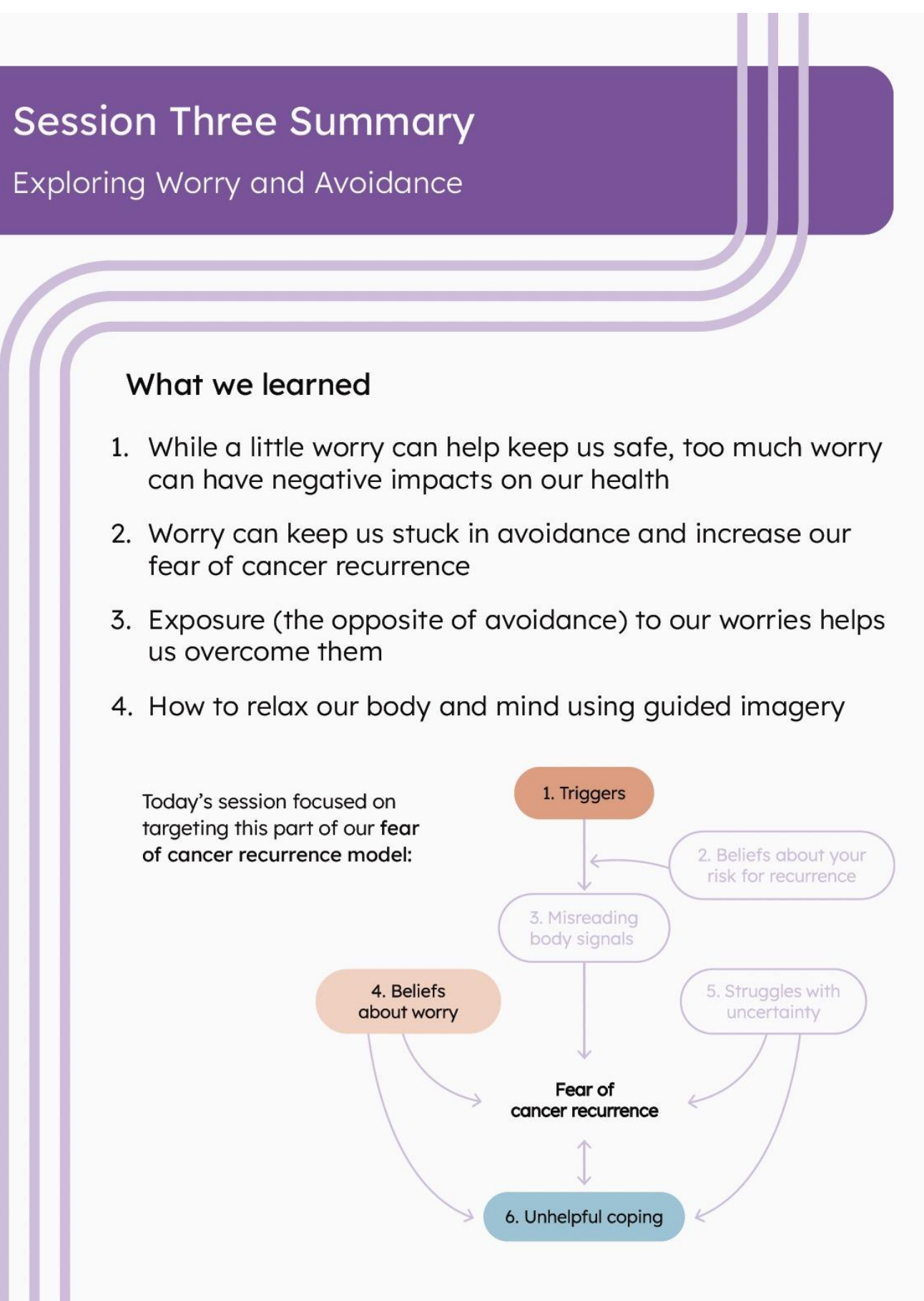
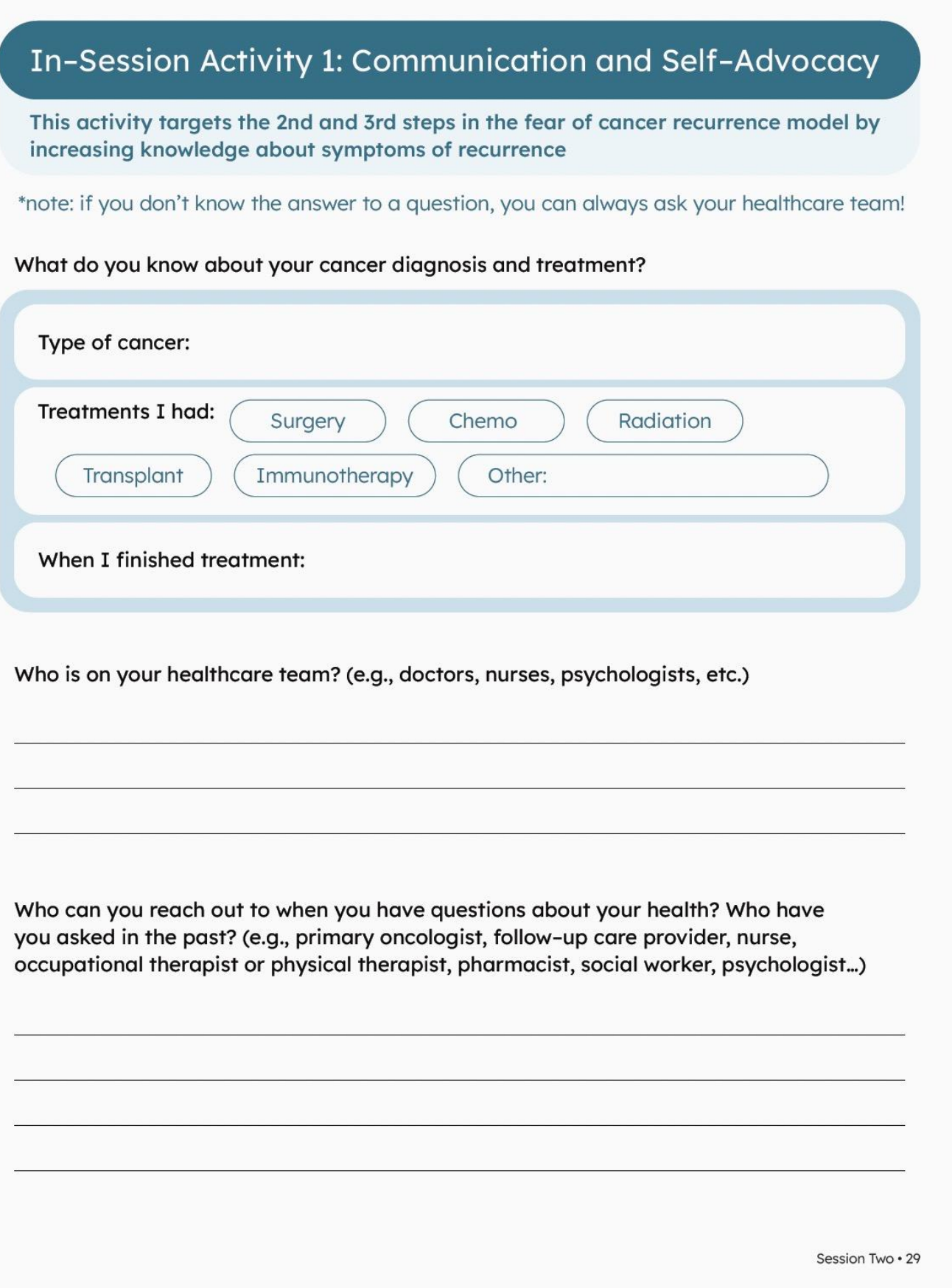
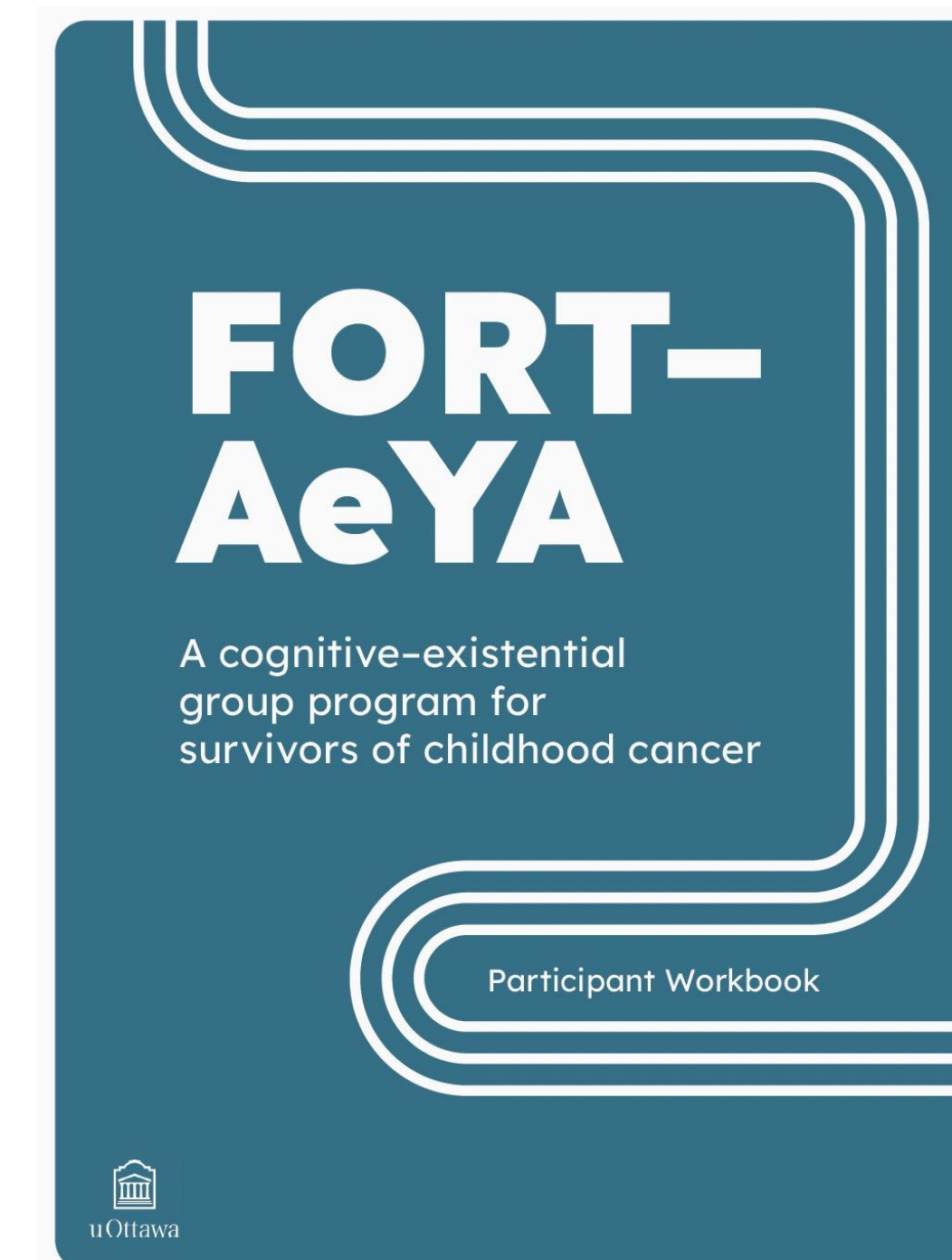
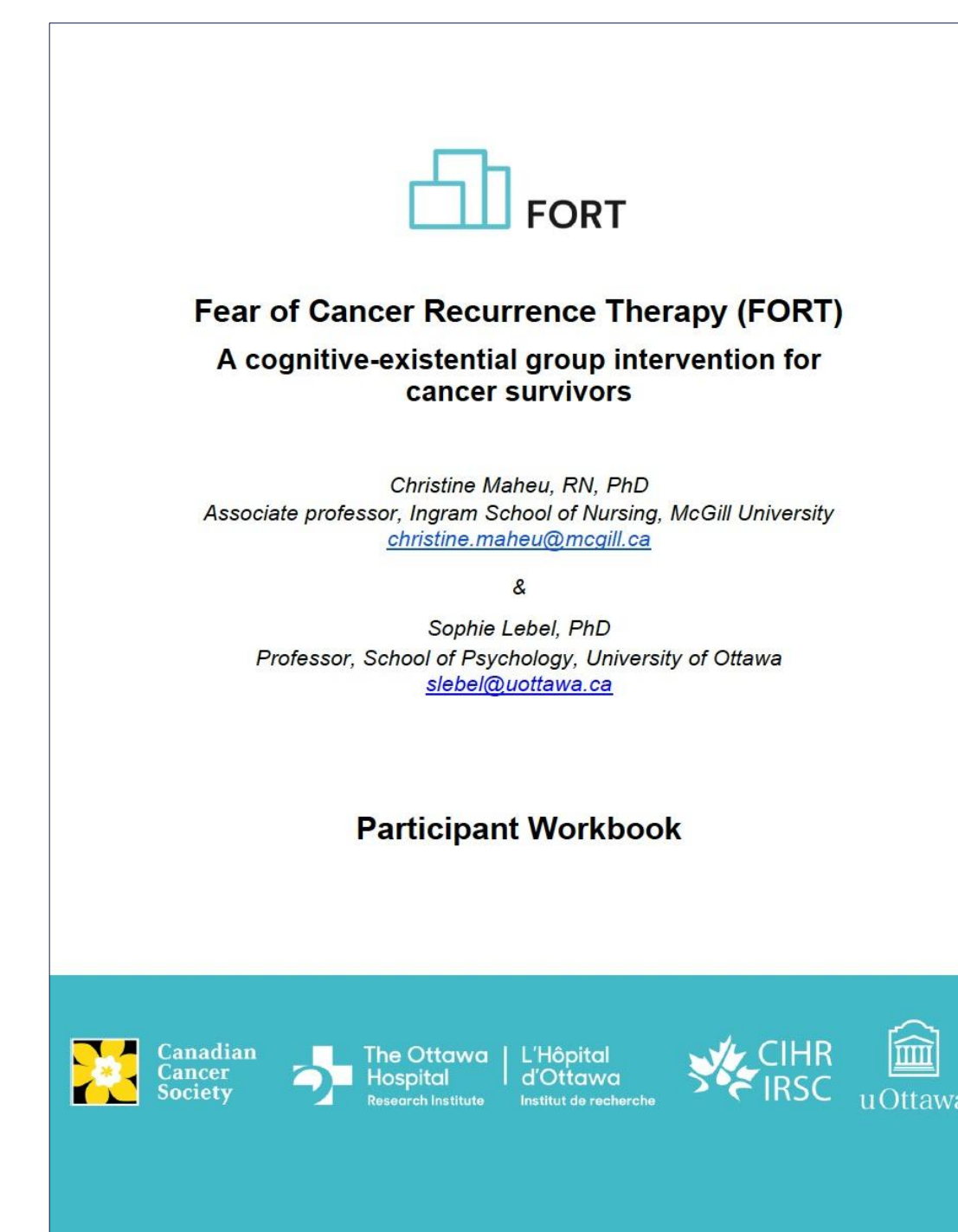
## Methods

### Adaptation

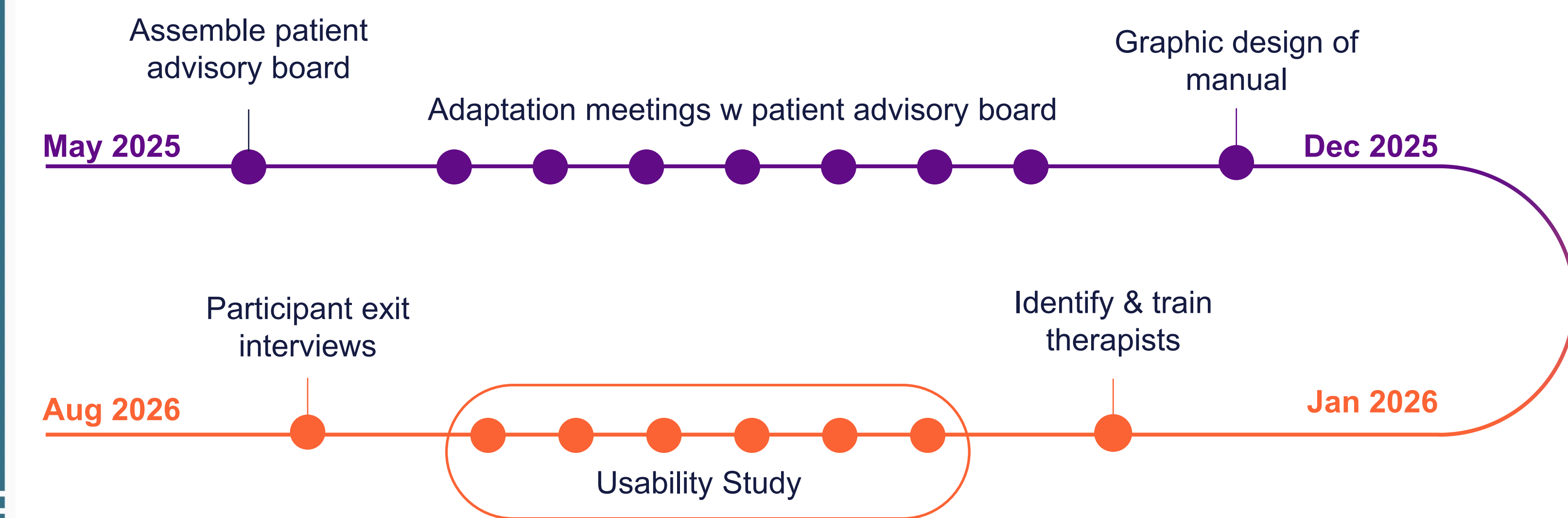
- Guided by the ADAPT framework
- Session-by-session modification of FORT manual via co-design with 2 patient partners and a 5-member AeYA advisory board
  - Adaptations tracked using FRAME framework
- Redesign of participant manual by graphic designer

### Usability study

- Participants: N = 9; ages 13-25; diagnosed with cancer ≤ age 18; ≥ 24 months post-treatment; clinically significant FCR (≥ 13 on the FCRI-SF or FCRI-C); residing in Canada
- Recruitment: social media, community organizations
- Data Collection (participants and therapists):
  - Each session: usefulness, usability, desirability, value, accessibility, credibility, readiness for end users
  - Exit interviews: what worked, what didn't, whether additional changes are needed (incl age span and diversity considerations)



## Study Timeline



## Preliminary Results

### Adaptation

- Major changes included:
  - Increased scaffolding and clarified instructions for all activities
  - Summary page after each session
  - Linked each session topic to FORT FCR model
  - Replaced visit from a healthcare provider with a module on self-advocacy and communication with parents and healthcare team
  - Added activities: coping toolkit; productive v unproductive worry; top 3 tools and wins
- Manual redesigned with professional graphic designer

### Usability study

- Anticipated results of usability study
  - Identification of any remaining adaptations needed
  - Feedback on usability, accessibility, and perceived value from survivors and therapists

## Impact/Outcomes

- Addresses a major unmet psychosocial need for survivors of childhood cancer
- Provides the first developmentally tailored FCR intervention for this population
- Positions FORT-AeYA for pilot testing and future implementation in survivorship care

## References

1. Lebel et. al., 2016; PMID: 27169703
2. Russell et. al., 2024; PMID: 39141180
3. Tutelman et. al., 2022; PMID: 35018689
4. Tutelman & Heathcote 2020; PMID: 33068463
5. Lebel et. al., 2014; PMID: 24756313

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