

Recovery Alberta

MENTAL HEALTH AND ADDICTION SERVICES

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MENTAL HEALTH AND ADDICTION SERVICES

Transitions for Youth and Young Adults with Eating Disorders and Mental Health Conditions: From Evidence to Practice



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MENTAL HEALTH AND ADDICTION SERVICES

Transitions for Youth and Young Adults with Eating Disorders and Mental Health Conditions: From Evidence to Practice

Addiction & Mental Health Knowledge Bites Lunch & Learn

Hosted by Recovery Alberta

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CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

McMaster University

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Agenda

- Background & Rationale
- The *TransitionED* Project
- Phase I – Evidence & Guideline Development
- Phase II – Co-design of the *TransitionED* Framework
  Today's Focus!
- Phase III – Piloting the *TransitionED* Framework
- Conclusion

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Background & Rationale

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What is a healthcare transition?

Young Canadians eventually age out of pediatric care
(Mackie et al., 2019; Toulany et al., 2022)

- Often occurs around age 18 (ranges between 16 to 19)
- Ongoing care may require new providers, programs, or systems
- Transition is more than simply transferring one's care

Healthcare transition:
"The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems."
—Blum et al., 1993, p.1



NICE, 2016

CAPHC, 2018

ED-specific transition research and practice is relatively new!

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Why are transitions important in ED care?

EDs often span this transition period

- Often emerge in adolescence and can continue into adulthood (Solmi et al., 2022; Treasure et al., 2005)
- Adult care may involve different services, expectations, eligibility, and care approaches
- Poorly-planned or -executed transitions can lead to delays, gaps, and discontinuation of care (Dimitropoulos et al., 2012)

ED transitions have added complexity

- Physical and mental health care aspects (Johnson et al., 2022)
- Caregiver roles change substantially (Nadarajah et al., 2021)
- ED symptoms themselves may affect motivation to continue treatment (Gregertsen et al., 2017)
- Recovery occurs alongside growing independence and other life transitions (Arnett, 2000; Hovish et al., 2012)

Yet, little is known about how to support transitions for young people with EDs specifically.

So, what does the existing evidence tell us?

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The *TransitionED* Project

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The *TransitionED* Project

- **Funder:** Canadian Institutes of Health Research
- **Grant:** Transitions in Care Phase 2
- **Title**: *TransitionED*: Co-Designing and Implementing Canadian Practice Guidelines for Transitions for Youth with Eating Disorders
- **Duration:** 2022-2026



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Phase I: Evidence & Guideline Development

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Project Overview



Phase I:
Complete ✓

Scoping review + six recommendations

To see our protocol paper, use this QR code!

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Scoping Review

- **Objective**: Map the evidence on pediatric-to-adult mental healthcare transitions for youth and young adults, including those with EDs
- **Methods**
  - Systematic search of 5 databases
  - Included YYAs ages 16–25 transitioning from pediatric to adult mental health services
  - Included EDs and other mental health concerns
    - Excluded studies focused only on neurodevelopmental disorders (e.g., autism, ADHD) due to distinct care pathways and treatment goals
  - Two reviewers independently screened records
  - Citation chaining used to identify additional studies
  - Extracted and synthesized findings into evidence tables

Organization of Included Evidence

Evidence type	Category	Short description	n	ED
Primary studies (n=199)	Descriptive	Describe transition patterns, characteristics & challenges	86	**6**
	Qualitative	Explore experiences, barriers, facilitators & recommendations	75	**15**
	Predictors	Identify factors associated with transition outcomes	48	**5**
	Transition interventions	Evaluate interventions supporting transition	21	**1**
	Measurement tools	Develop or evaluate transition-related measures	8	**0**
	Key outcomes	Identify important transition outcomes through consensus	3	**0**
Other studies (n=220)	Reviews	Synthesize existing transition literature	57	**3**
	Commentaries	Discuss transition challenges & proposed solutions	91	**8**
	Grey literature	Guidelines, reports, presentations & abstracts	47	**2**
	Books/book chapters	Discuss pediatric-to-adult mental healthcare transitions	12	**3**
	Study protocols	Describe planned transition research	18	**2**

Note: Some studies or records are reported in multiple categories.

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What do ED-specific studies tell us about transitions?

- Pathways after pediatric ED care vary considerably
  - Youth transition to adult ED services, primary/community care, remain in pediatric care, or receive no ongoing treatment (Arcelus et al., 2008; Gilsbach et al., 2024; McClelland et al., 2020; Steinegger et al., 2018)
  - Age, prior service use, and duration of pediatric ED care are associated with transition outcomes (McClelland et al., 2020; Reneses, 2020; Stagi et al., 2015)
- Service structures shape what happens
  - Age cut-offs and adult eligibility criteria disrupt continuity (Winston et al., 2023)
  - Formal transition protocols are not consistently available (Someshwar et al., 2015)
- Youth, caregivers, and providers identify important transition needs (Brewin et al., 2022; Dimitropoulos et al., 2012, 2013, 2015, 2016; Gilsbach et al., 2024 ; Lockertsen et al., 2020a, 2020b, 2021; Mooney et al., 2023; Nadarajah & Couturier, 2020; Nadarajah et al., 2021; Scanferla et al., 2023; Wales et al., 2021, 2022)
  - Developmentally-appropriate timing, rather than age alone
  - Continued caregiver involvement
  - Information sharing and medical monitoring
  - Bridging treatment cultures between the pediatric and adult care environments
  - The emotional impact of transition

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Transition Interventions

Intervention	Approach	Key finding
Managed Transition (MT) – Europe (8 countries) (Singh et al., 2023)	CAMHS training + identification + TRAM assessment/feedback	28% vs. 22% transitioned to AMHS; parents more prepared/satisfied
Youth Transition Project (YTP) – Canada (Cappelli et al., 2016)	Individualized transitional care plan	59% transitioned to AMHS; median/mean time to transition 110 days
"Protocol" – Italy (Gatta et al., 2021)	Structured CAMHS→AMHS transition protocol	94% vs. 54% accessed adult services
National transition requirements – USA (Sawicki et al., 2011)	Transition counselling/planning	55% discussed changing needs; 53% adult insurance; 62% school transition plan
Transition Intervention for Eating Disorders (TIDE) (ED-specific) – Canada (Nicula et al., 2023)	Peers + transition meeting + primary care + navigation	7/10 completed; 75% of components completed; acceptable/helpful; limited adult-care connection

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Measurement Tools

Measure	Key features	Evidence
Transition Readiness and Appropriateness Measure (TRAM)	**64 items** Youth, parent & clinician versions Healthcare knowledge, self-management & communication	Kunczicky et al., 2023 Santosh et al., 2020
Readiness Assessment of Independence for Speciality Encounters (RAISE)	**5–26 items** Developmentally staged (birth–21) Self-advocacy, health knowledge & navigation	Shanske et al., 2021
Transition Readiness Assessment Questionnaire 5.0 (TRAQ 5.0)	**20 items in 5 domains** Self-management, health knowledge & healthcare navigation	Allemang et al., 2022 Allemang et al., 2023 Cleverley et al., 2022 Cleverley et al., 2023

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Guideline Development

- **Objective**: Develop evidence-informed recommendations for pediatric-to-adult transitions in ED care
- **Methods**
  - Scoping review findings informed draft recommendations
  - Reviewed by a Guideline Development Panel of youth/young adults, caregivers & clinicians
  - Panel considered:
    - Strength/certainty of evidence
    - Generalizability
    - Stakeholder values & preferences
  - Recommendations refined through discussion and consensus
  - Modified Delphi: ≥70% agreement required
  - Consensus achieved after one voting round

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Guideline Recommendations

STRONG

- Implement integrated, collaborative transition models to support continuity between pediatric and adult care
- Strengthen transition research and evaluation, including long-term outcomes and key transition outcomes (e.g., acceptance, transfer, treatment discontinuation, discharge)
- Use the TRAQ to assess transition readiness, particularly in mental health; further study is needed in EDs

WEAK

- Consider the TRAM to assess transition readiness and appropriateness
- Consider the RAISE to assess autonomy and self-management

TRAM and RAISE require further study, particularly in EDs

To see the Guidelines, use this QR code!

Phase II: Co-design of the *TransitionED* Framework

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Project Overview



Phase I:
Complete ✓

Scoping review + six recommendations

Phase II:
Wrapping up

- Co-design workshops across Canada
- Identified barriers across clinical contexts
- Co-developed and refined the TransitionED framework

Methods

- **Purpose**: to co-design locally-relevant strategies for implementing national ED transition guidelines with youth and young adults (YYAs), caregivers (CGs), ED specialists (EDSs), and community organization representatives (CORs)
- **Design**: Qualitative Description (Sandelowski, 2000); informed by community-based participatory approaches and implementation science frameworks
- **Recruitment**: Partners with relevant lived or professional experience were identified through existing project partnerships, recruitment posters, and partner networks, representing four groups: YYAs, CGs, EDSs, and CORs
- **Data Collection:** Three virtual co-design workshops combining small breakout room discussions and whole-group discussion/report back
- **Data Analysis:** Conventional content analysis (Hsieh & Shannon, 2005) and Framework Method (Gale et al., 2013; Goldsmith, 2021)

Participant Characteristics

	All (n=46)	YYA (n=9)	CG (n=5)	EDS (n=17)	COR (n=15)
Sex, Female	85%	100%	100%	71%	87%
Gender, Woman	85%	100%	100%	71%	87%
Average age	43.04	24.22	55.80	44.63	48.40
Ethnicity, White	74%	67%	100%	76%	67%
Province, Ontario	41%	44%	20%	41%	47%
Province, Alberta	20%	22%	40%	6%	27%

- **YYAs:** All had Anorexia Nervosa; some also had Bulimia Nervosa or Binge Eating Disorder; all had received ED treatment
- **Caregivers:** All were parents; their children had mostly experienced AN and received ED treatment
- **ED specialists:** Primarily from specialized ED programs, with representation from psychology, pediatrics, and psychiatry, across pediatric and adult care
- **Community organizations:** Represented diverse settings, including national ED organizations and provincial integrated youth services, offering resources, peer support, helplines, education, and other forms of support

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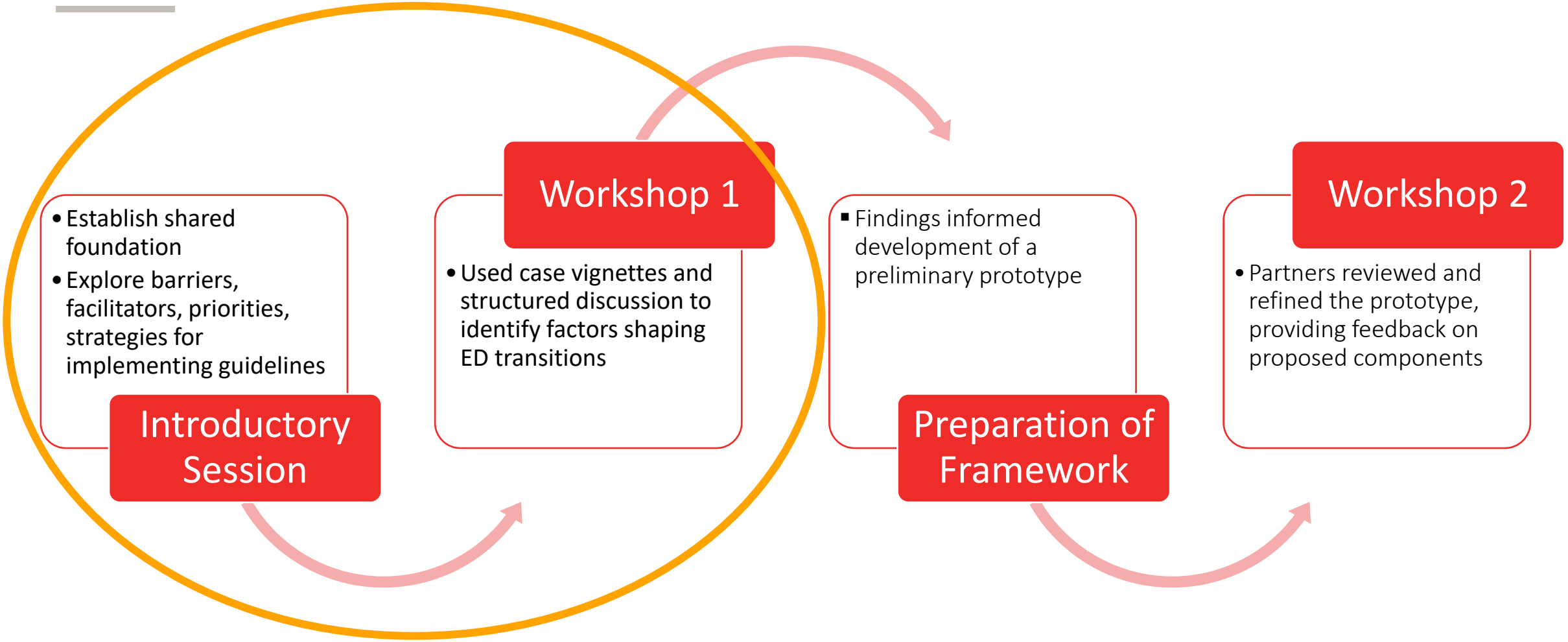
Structure of Co-design Workshops



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The Realities of ED Transitions

- **Transition is more complex than simply pediatric → adult care**
- YYAs follow varied care pathways as they approach adulthood (e.g., adult ED care, community, primary care, other mental health services, or not at all!)
- The transition period coincides with changes in autonomy, confidentiality, responsibility, caregiver involvement, and more
- YYAs are often navigating multiple transitions at once: levels of ED care, school/ post-secondary, geographic moves, changing providers/healthcare systems
- Pediatric and adult services are fundamentally different with regards to treatment intensity, environment, expectations, age mix, family involvement, and more
- Families often rely on providers to guide transition decisions; meanwhile YYA and caregiver preferences may differ

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Current ED Transition Practices

- **There is no single, consistent transition model or approach across ED services**
- Transitions are often described as a "work-in-progress", with substantial variation across specialized ED programs
- Age boundaries vary; some have rigid cut-offs at 18, others extend care to 19, 22, 25, or operate as lifespan programs
- Transition planning often depends on what the YYA wants and the practices/resources of the individual program
- Some programs aim to complete treatment before age-based discharge OR retain youth longer to avoid treatment disruption
- Adult programs use various transition-supportive practices (e.g., family educators, case discussions/joint meetings, expedited/fast-tracked access)

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Factors that Shape ED Transitions

YYA-level	Family-level
• Comorbidities • Transition hesitancy • Balancing intensive treatment with school • Uncertainty about adult care • Varied readiness for greater autonomy	• Sudden changes in caregiver involvement • Different YYA/caregiver preferences • Financial, time, and resource constraints • Burnout
Program-level	**System-level**
• Rigid pediatric age cut-offs • Retelling one's story after transfer • Adult care may be less intensive/flexible • Different treatment philosophies	• Long waitlists for adult services • Geographic and access barriers • Public and private coverage differences • Limited connectivity across services

Factors that Facilitate ED Transitions

- Warm handovers and collaboration between pediatric and adult services
- A consistent person to help the YYA/CGs navigate the transition
- Someone to accompany the YYA/CGs to the new system
- Providers who understand both sides of the transition
- Continued, negotiated caregiver involvement and information-sharing
- Prioritizing the YYA's needs and preferences, while gradually increasing autonomy
- Information about the destination service to be shared earlier
- Flexibility based on readiness, resources, geography, and individual circumstances

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Suggestions: *When should transition happen?*

- Introduce the possibility of transition **early** in care, with more focused discussions ~1y before transition
- Develop health management, decision-making, self-advocacy, and other transition skills **gradually** throughout pediatric care
- Transition should be **based on readiness**, capacity, treatment needs, and individual circumstances
- Increase flexibility around age cut-offs
- Allow for overlapping periods of parallel pediatric and adult care where possible

**Participants acknowledged feasibility challenges when assessing readiness for each individual YYA.*

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Suggestions: *What do YYAs and CGs need?*

YYA & Caregiver-facing Supports

- Practical supports that prepare, inform, and accompany YYA and caregivers:
  - Planning workbook/decision tool
  - Personal profile (detailing health info, needs, preferences)
  - Joint transition meeting/warm handover (with incoming and outgoing providers)
  - Post-transition meeting summary, clarifying roles, responsibilities, next steps, and the plan
  - Navigation and interim support (e.g., community, post-secondary resources)
- Content should focus upon:
  - Differences between pediatric and adult care
  - Changing caregiver role and confidentiality
  - Adult care options and destination programs
  - Healthcare management, decision-making, and self-advocacy

Suggestions: *What else needs to change?*

Program- & System-level supports

- Improve communication and collaboration within and between pediatric and adult ED services
  - Establish regular opportunities to discuss cases, waitlists, eligibility, and more
- Consider alternative services structures (e.g., lifespan, TAY-specific)
- Maintain continuity across services
- Strengthen primary care, community, post-secondary, and other interim supports
- Use standardized transition guidance/checklists, while allowing for local adaptation to context, staffing, and resources

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Suggestions: *Last Few Points*

- YYA suggested that an ED-specific transition readiness measure is developed
  - To rely less on chronological age
  - To capture multiple dimensions of readiness and capacity, relevant to EDs
- A bridge to conceptualize transition
  - One CG noted that their child made sense of the transition by viewing pediatric and adult care as two sides of a bridge
  - Rather than telling YYAs to simply "cross" into adult care, transition supports could help YYAs and caregivers "walk across”
  - This helps illustrate transition as a supported process between systems, rather than a single transfer event

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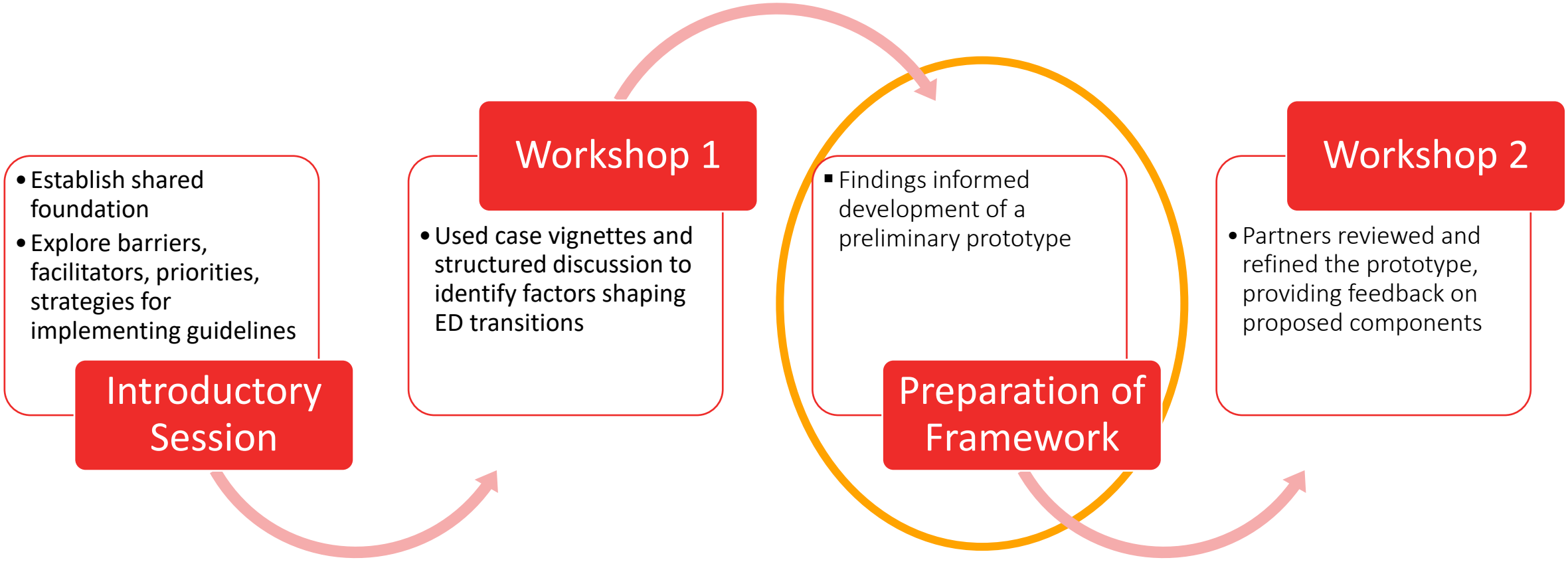
Structure of Co-design Workshops



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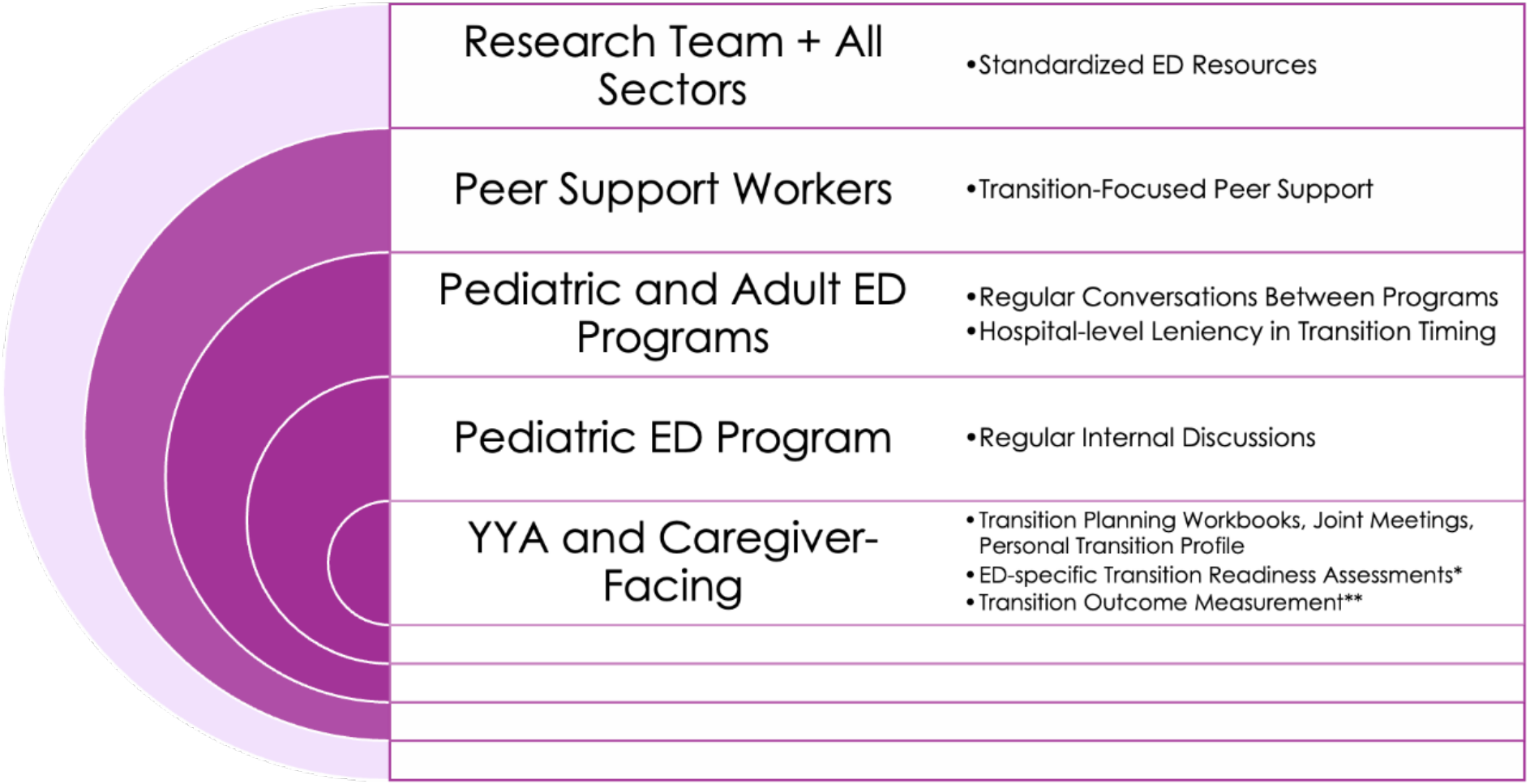
Prototype TransitionED Framework (based on IE and W1)



*Measurement Tools; ** Transition Outcomes

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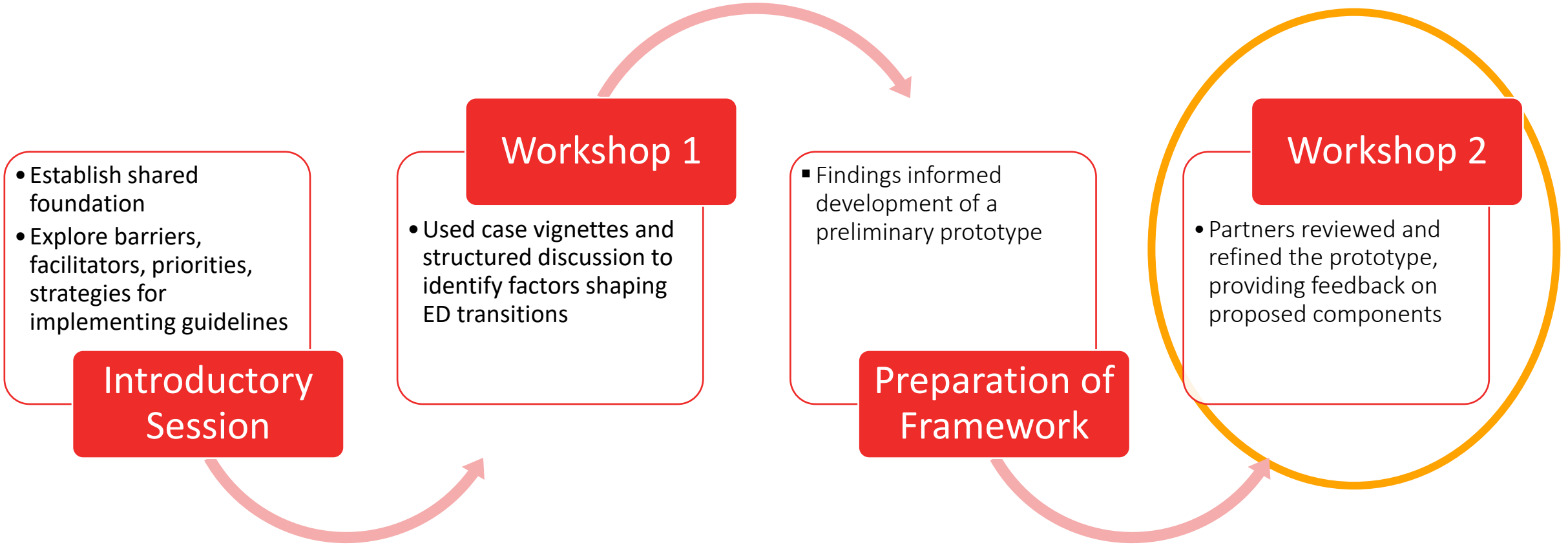
Structure of Co-design Workshops



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Refinement of and Feedback on Prototype (based on W2)

- Overall, the framework was broadly supported, but flexibility was requested
- Offer materials in multiple forms, with a focus on usability
- Personal Transition Profile – person-centered, collaboratively-created, and sensitive to what information the YYA wants to see
- Joint Meetings – should prepare the YYA for the experience of adult care, not merely be a transfer of information
- Caregiver involvement should be negotiated, not just switched off!
- Partner with, and strengthen, existing infrastructure (e.g., resources, peer support)
- TRAQ-ED should guide transition planning, but **does not** determine readiness
- Transition success is not equal to entry into adult ED care or symptom improvement

Refined TransitionED Framework (after W2)

YYA/Caregiver-facing Components

Team/System Support

Transition Planning Packages	Personal Transition Profile	Peer Support Sessions	Transition Meetings	Communication & Collaboration Guide
Separate package for YYAs and Caregivers	YYA-authored snapshot; centering youth voice	One-time, group sessions offered separately	1: Clinician-led transition planning and preparation	1: Regular communication *within* the pediatric ED team
Journal-style; tailored to YYA's individual path/life	Relational, contextual, & preference-based information	Youth-to-Youth and Caregiver-to-Caregiver	2: Connection with incoming/adult providers; rapport, plans, timelines	2: Collaboration *between* outgoing and incoming providers

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Phase III: Piloting the *TransitionED* Framework

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Project Overview



Phase I:
Complete ✓

Scoping review + six recommendations

Phase II:
Wrapping up

- Co-design workshops across Canada
- Identified barriers across clinical contexts
- Co-developed and refined the TransitionED framework

Phase III:
Preparing for launch!

- Approvals underway
- Implement and evaluate at two Canadian ED programs

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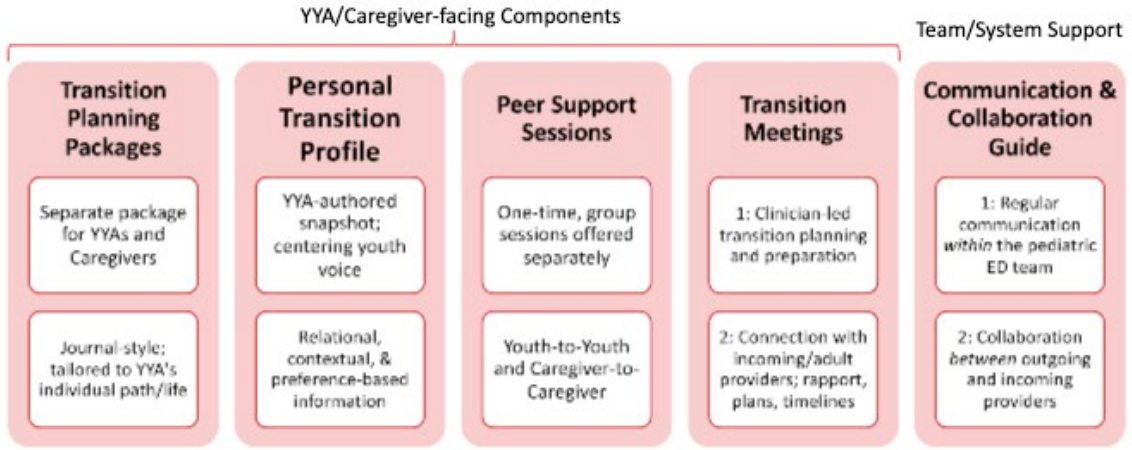
Phase III: Implementation & Evaluation

Pre-implementation – *we are here!*

- Ethics and institutional approvals underway
- Tailoring TransitionED to each site
- Building the implementation teams and identifying the clinicians



Implementation

- 30 families (young person + their parent) across 2 sites
  - Calgary: 15 | lifespan program; Hamilton: 15 | pediatric → adult care
- Deliver & track TransitionED components
- Measures at pre, post, and 6mo follow-up, with interviews with the young person and parent at post

Post-implementation

- Interviews with clinicians and implementation teams

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Conclusion

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Conclusion

- Transitions in care for YYAs with EDs and mental illness are often marked by disruptions, poor planning, and gaps in continuity
- Evidence to guide transitions remains limited, particularly for YYAs with EDs
- We proposed six recommendations to guide research and clinical efforts to improve these transitions
- Our co-design findings reinforce the need for both individualized YYA/caregiver supports and program- and system-level change, including early and flexible planning, continuity across services, practical transition supports, and assessment of transition readiness and outcomes
- Future work should develop, evaluate, and implement equitable, context-responsive approaches to improving transitions in ED care

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Questions?

Thank you for attending!

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