# CONTEXT MATTERS: CAPTURING EXPERIENCES OF MENTAL HEALTHCARE FOR YOUNG PEOPLE

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myEXP App

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# Child and youth mental healthcare: *Context matters*

- Young people with mental disorders often require multiple services
- Yet there is not single ‘mental health system’
  - services offered may vary considerably based on local context
- Two key challenges put young people at risk:
  - Poor coordination across services
  - Ineffective transitions from youth to adult mental health care
- How to make care more youth, family AND provider centered within the local context?

# Experience-Based Co-Design

- Approach is rooted in the design sciences
- First used in UK health care in 2005, early use in Canada
- Often retrospective, in-depth interviews, video capture
- Identify ‘touch points’ in experiences
- Key stakeholders work together to co-design solutions
- Questions:

1. Can we use real time data-gathering through use of smart phone app to engage young people in EBCD?
2. Will this facilitate co-design of solutions that are responsive to local context?

# Research Questions:

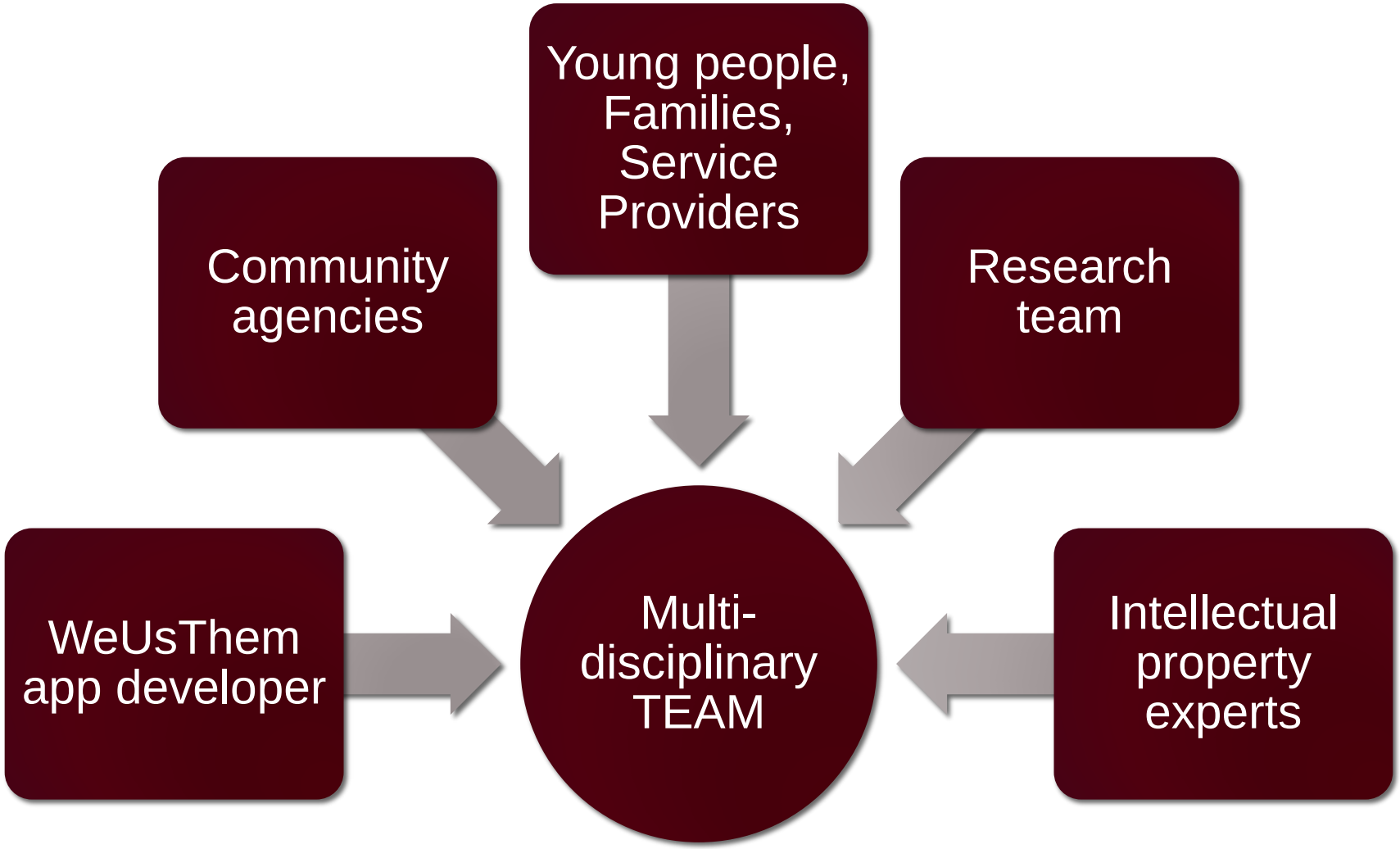
How can EBCD be used to co-redesign improved transitions and coordination of care experiences for youth with mental disorders?

- **Can smart-phone technology ENGAGE** young people experiencing mental healthcare in mapping real time service use and experiences?
- **What are the 'TOUCH POINTS'** that shape care coordination and transition experiences?
- Can young people, family members and providers effectively use design principles to **CO-DESIGN interventions** and improve experiences at these touch points?
- **What are the CONTEXTUAL barriers and facilitators to implementation** at the policy, local service system and service organization levels?

# Methods

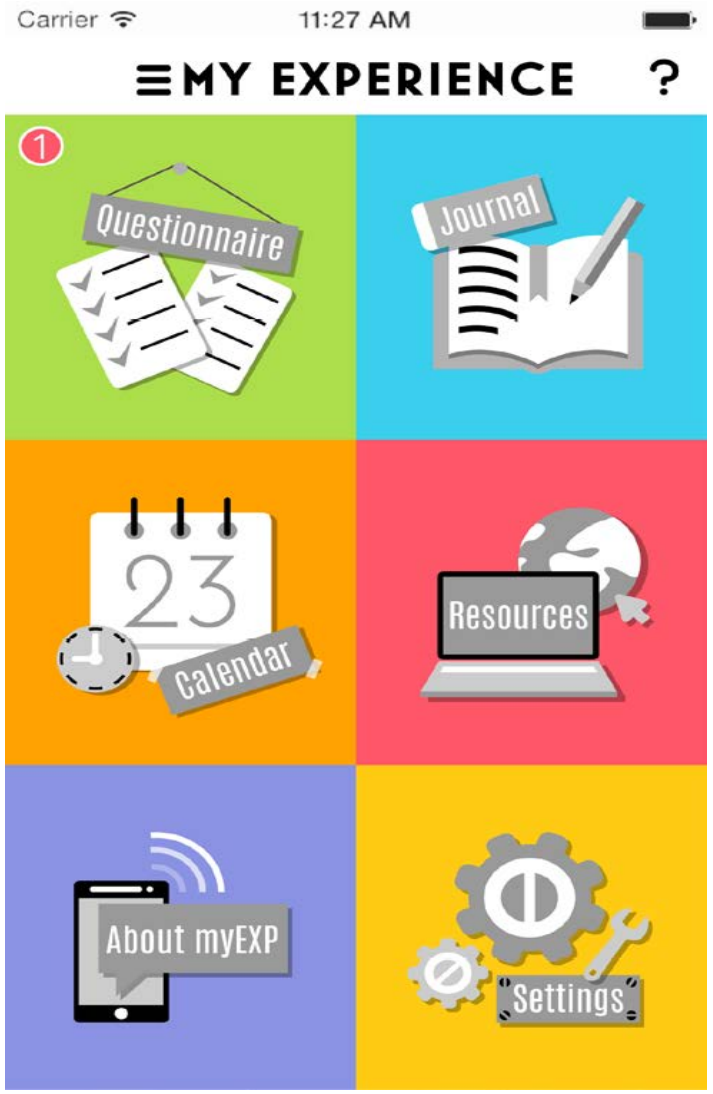
- Case study approach, community-engaged research
- The Case: “experiences of service coordination and transitions to adult care for youth with mental disorders in Ontario”
- Sampling – maximize variation:
  - Youth age (16-24), sex
  - Diagnosis (depression, anxiety disorder, bi-polar disorder, post traumatic stress disorder, personality disorder/behavioural)
  - Multiple agency/service delivery organizations
  - 3 Local LHINs
- Recruitment:
  - Recruitment through mental health service provider
  - 17 youth, family members, and service providers

# Our partnerships

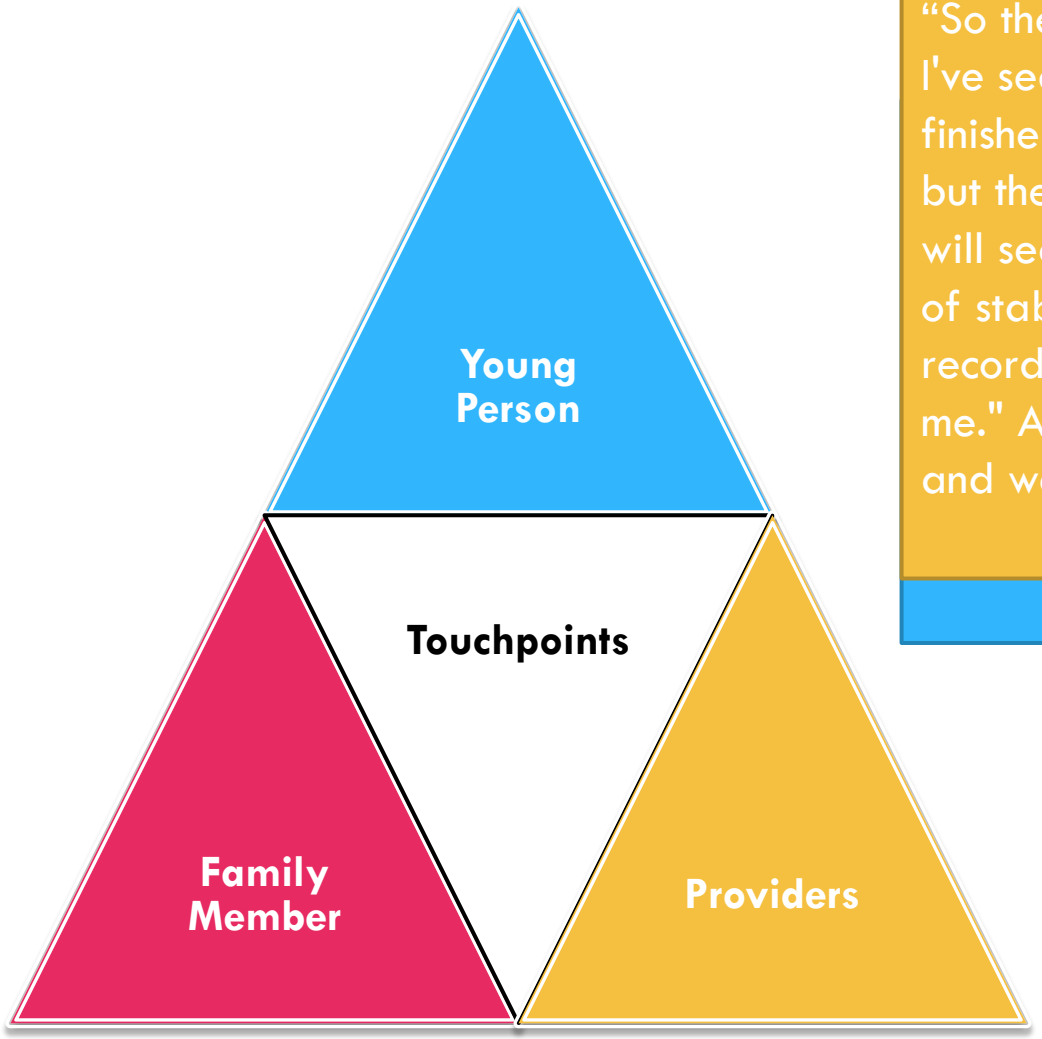


# My EXP Apps

- Suite of apps for youth (smartphone), family member and service provider (web apps)
  - Youth enters scheduled appointments
  - Following appointment each participant is prompted to complete brief questionnaire to record experiences
  - Youth has option to make free hand entries at any time
  - parallel interviews: intake, 6, 12 months



# Context finding: Working around the system

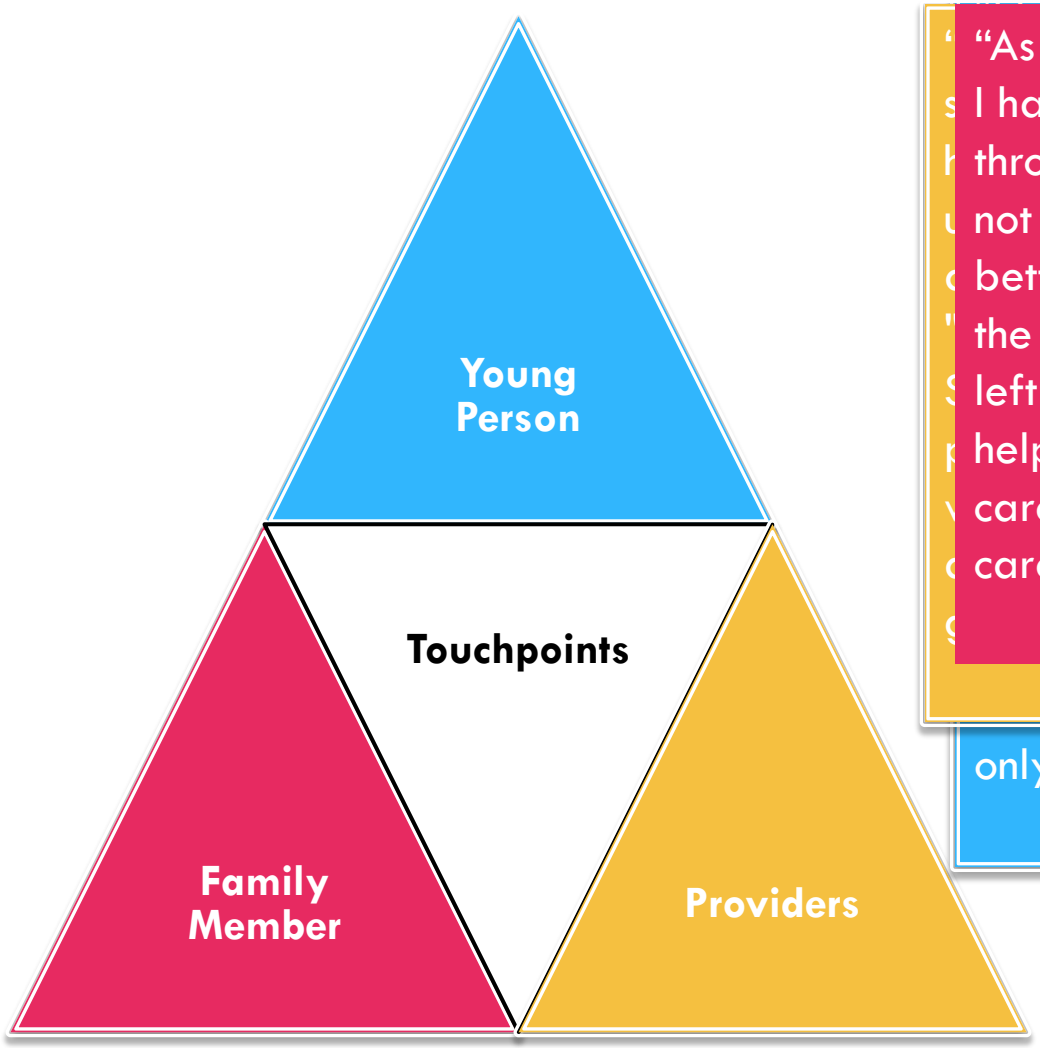



"So the reality is we do end up seeing kids-- I've seen her since grade 9. She's almost finished grade 12 now. Technically that's not-- but the way I've kind of worked around it is I will see them for four, six, or eight sessions, kind of stabilize them, then, at least as far as the records go, discharge them and then say, "Call me." And then they come in as new referrals and we start the whole process again.

-Social worker

-Young person

# Context finding: Communication matters




"As a result it's very-- I feel like I'm proactive or I have to go in the dark and feel my way through. That's where, if there was some way to, not so much keep me informed but to keep me better equipped to work with her and work with the team rather than be left to guess…So I'm left at a loss and what do I do, it would be helpful to not just give the person the term caregiver, but actually treat them as a fellow caregiver. "

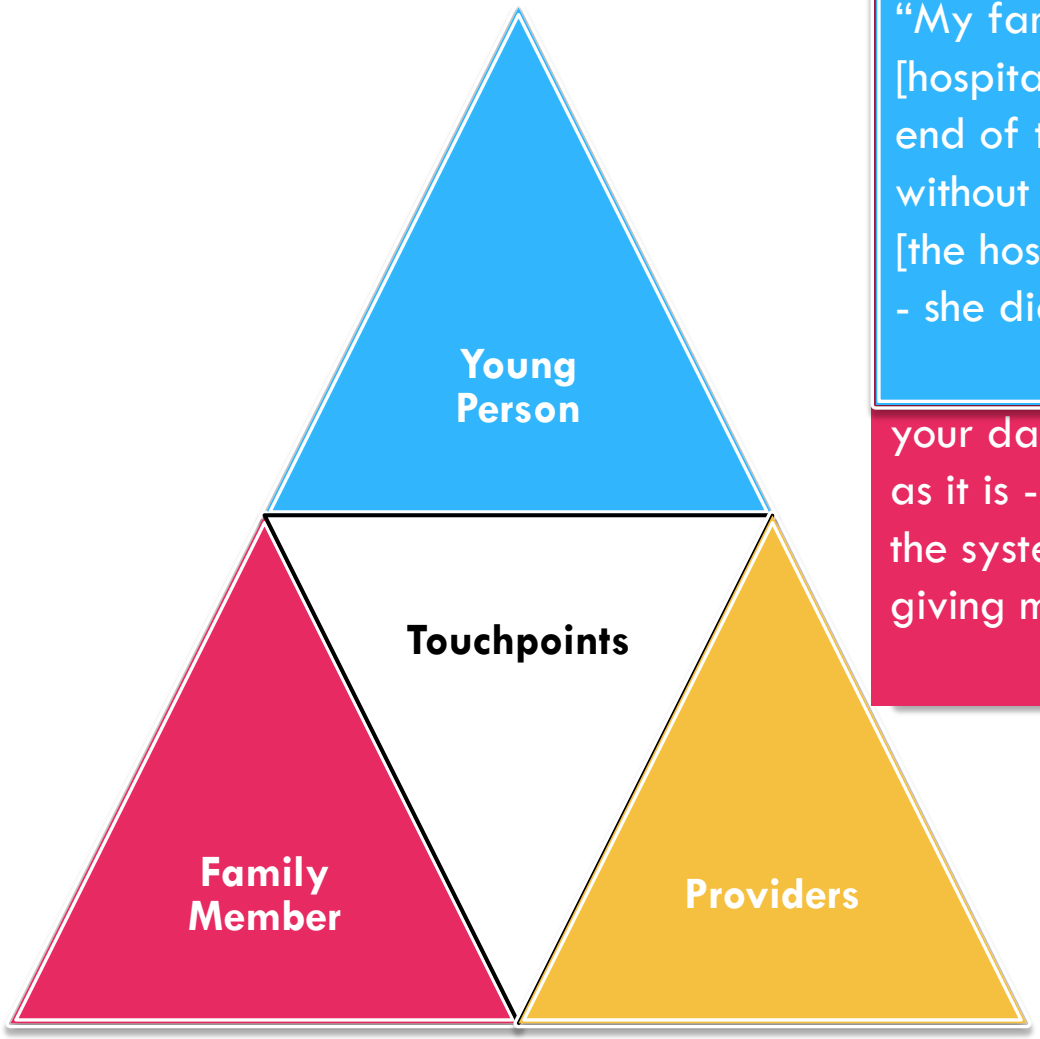
-Parent

-Psychiatrist

only myself, but to others."

-Young person

# Context finding: Information sharing matters



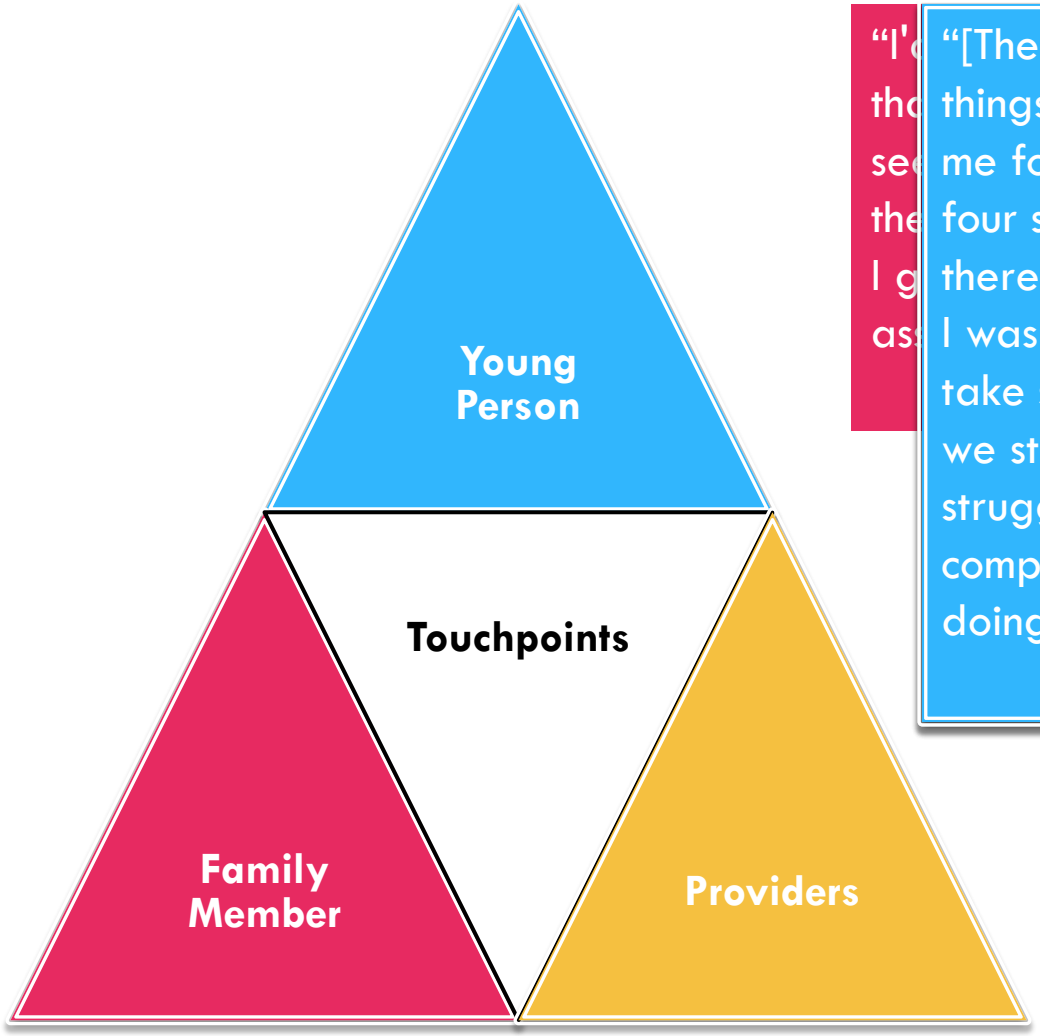

"My family doctor told me that I was going to [hospital] for some testing, and I'd be out at the end of the day. I didn't leave. She pretty much, without telling me…she tricked me into going to [the hospital]. She told them what was going on - she didn't tell me."

-Young person

your daughter there - who's in a very fragile state as it is - and being told no. I'm trying to work with the system and helpful but the information you're giving me is not accurate."

-Parent

# Context finding: feeling understood matters

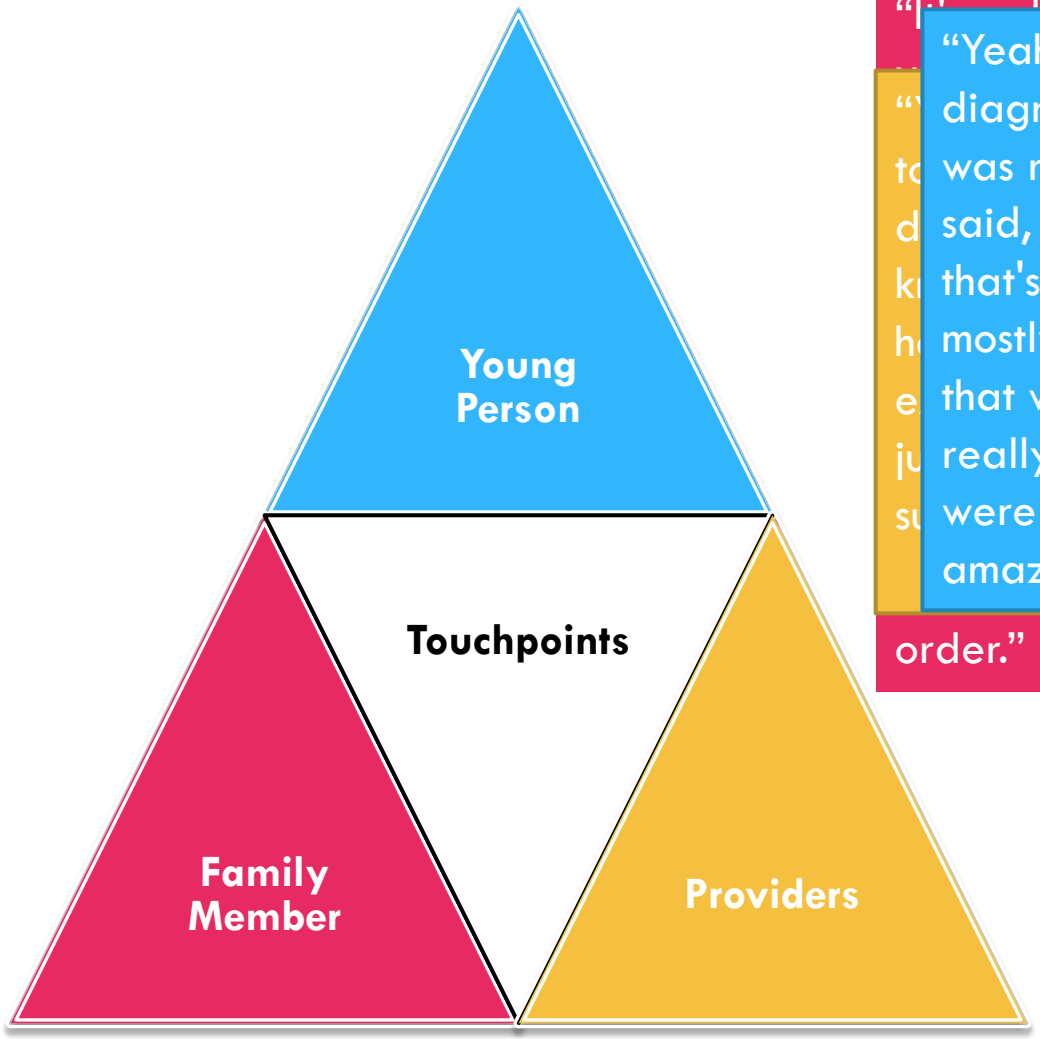



"I' tho se the I g as

"[The counselor], instead of rushing right through things, she actually took the time to get to know me for who I was...And I think she took a good four sessions - four hour-long sessions - to just sit there and get to know me and get to know what I was about, what happened to me, actually take some interest in what I was about, and then we started treatment. I enjoy it because I still do struggle with self-harm and stuff. I'm still not completely better, but she doesn't shame me for doing it."

-Young person

# Context finding: Relationships matter

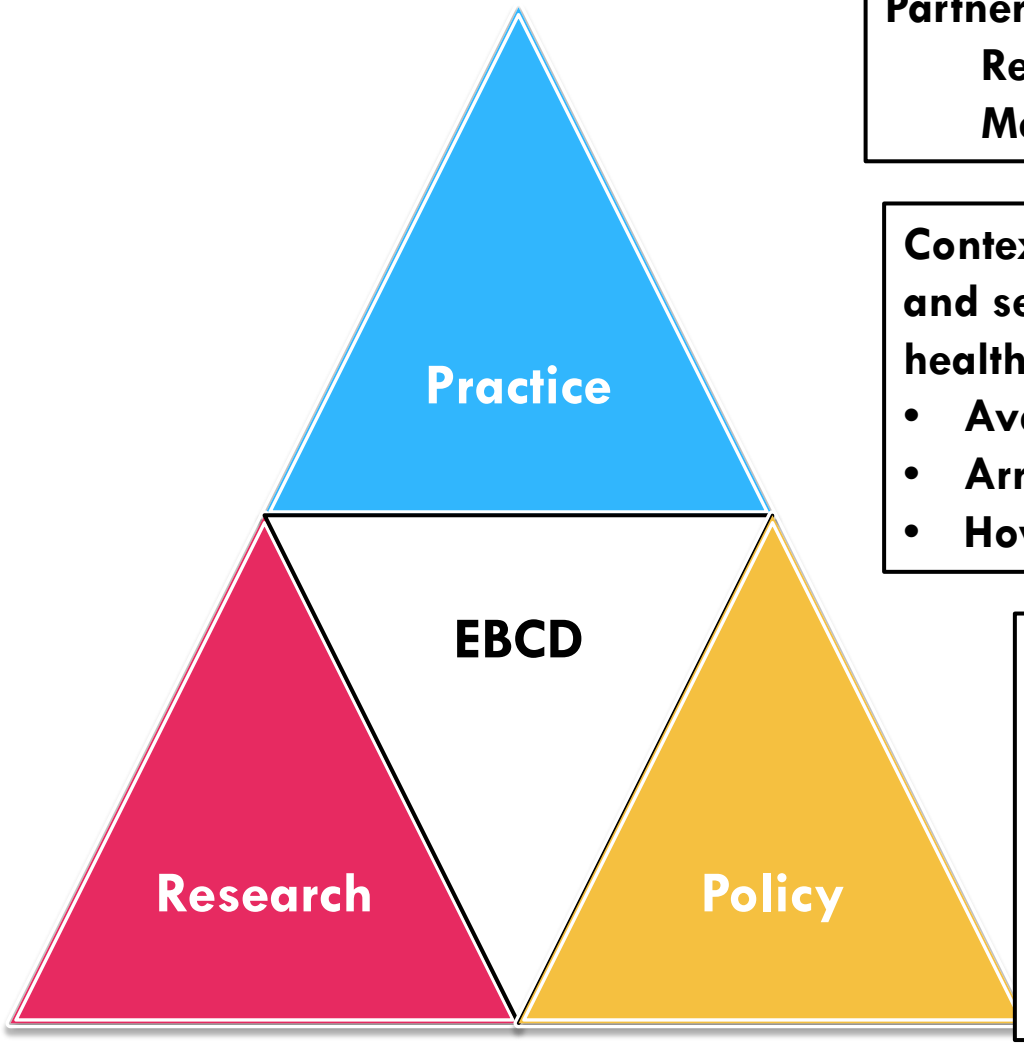



"Yeah, because she's really the one who diagnosed me and was like, "Yes, I see." She was really the first one that believed me when I said, "I have a problem." She's been the one that's been like, "Okay, I believe you." She's mostly been my backbone and been the one that when I'm really doubting myself, that's been really reassuring and been like, "[Name], you were out of hospital for a year. That's amazing."

-Young person

order."

# Implications




**Partnerships matter**
- **Research design**
- **Mental healthcare services**

**Context shapes service users', family members' and service providers' experiences of mental healthcare:**
- **Availability of services**
- **Arrangement of services**
- **How YP, FM, and SP can interact**

**The use of EBCD and technology, can be a major opportunity:**
- **For INNOVATION in research and practice**
- **For COORDINATION of care**
- **For TRANSITIONS for young people –** *how steep is the cliff?*

# Final Thoughts

- Technology presents an opportunity to engage youth demographic in mental health research.
  - Less stigmatizing
  - Assists youth in tracking appointments
  - Immediate access to resources for support
- Benefits to Research:
  - Data collection follows the user
  - Captures real time experiences, reduces risk of recall bias
  - Opportunity to compare data gathered on experiences through app versus traditional interviews
- Potential for other applications:
  - evaluation studies; rapid improvement cycles; inform delivery; other ages/health concerns.

# Acknowledgements and Contact Info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- We want to acknowledge wonderful work of our software developers WeUsThem.
- Thanks to the full research team:
  - Ashleigh Miatello
  - Christina Hackett
  - Alison Mulvale


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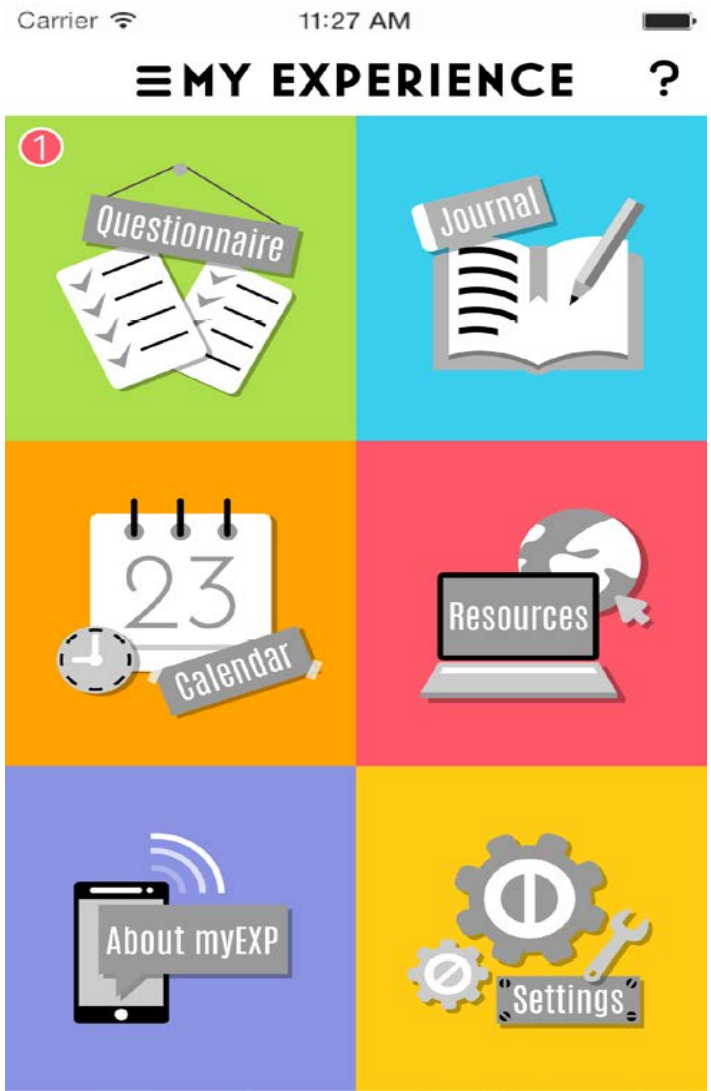
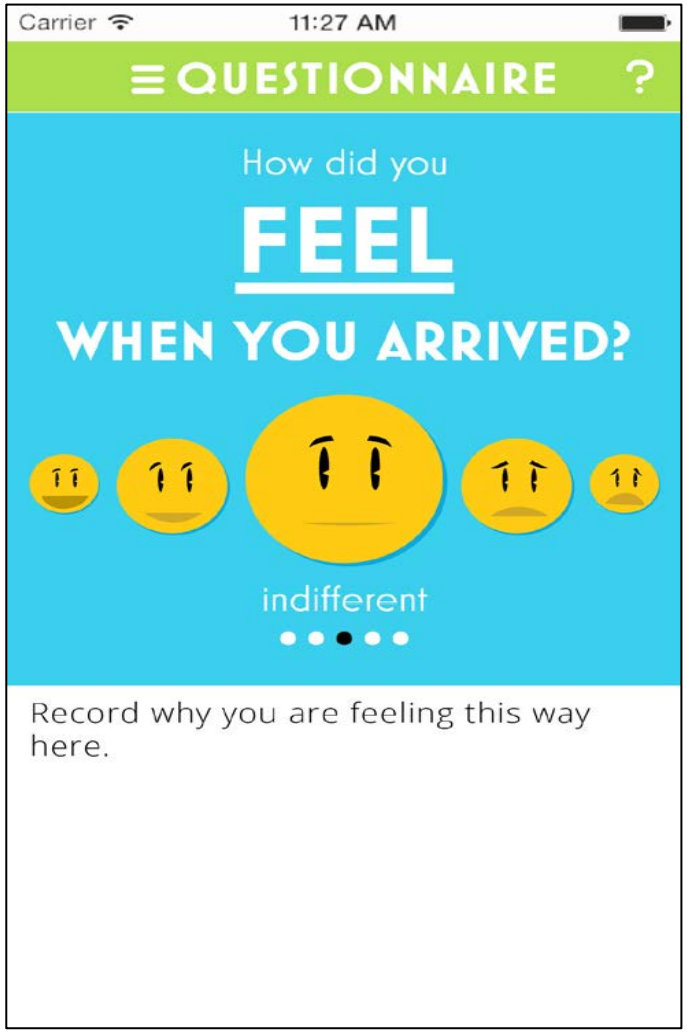
# APPENDICES

# Home Screen




- Formal questionnaire
- Option for comments at any time, even if not currently receiving services
- Calendar
- Resources
- Help Screens
- Settings

# Data Collection through APP




- Asks youth about feelings and experiences
- Various stages of the journey through services
- Combination of feelings scale and open-ended questions

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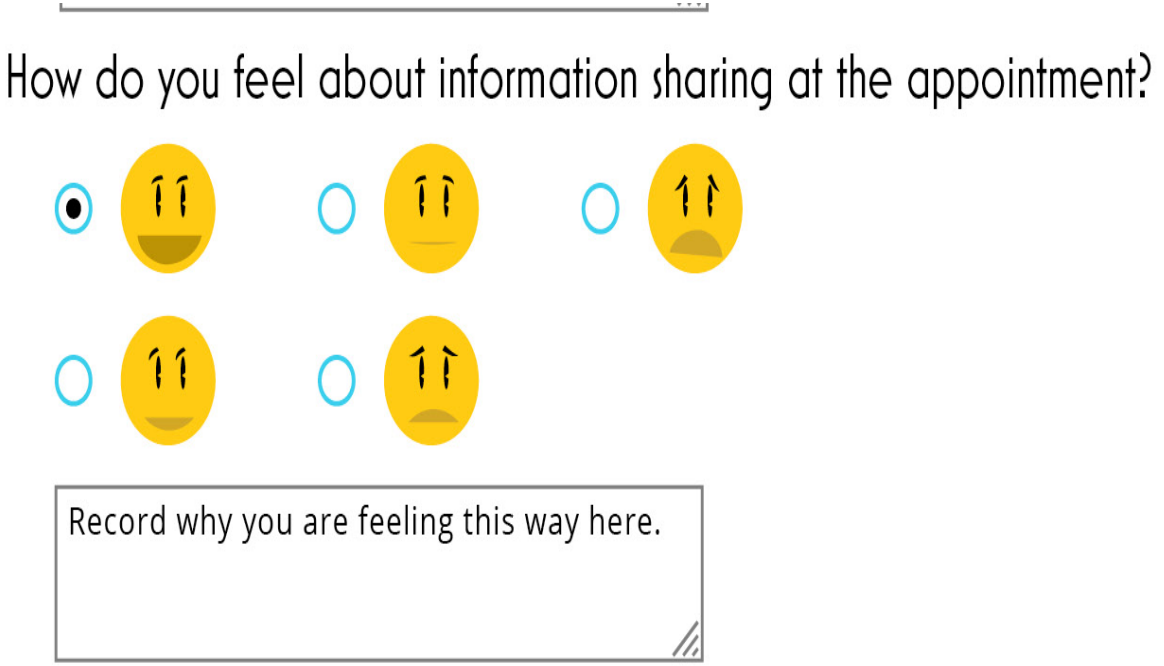
# Web Application:

- For service providers and family members
- What are their experiences as the young person travels through the system?



# Incentives

- Key challenge is to keep young people engaged and using the app for a year.
  - We will provide a series of scheduled honoraria to youth for continuing to use app, participate in 3 scheduled interviews and if applicable, later stages of study
  - Family members will received honoraria for participating in 3 schedule interviews and if applicable, later stages of study.
- We will also check-in by phone after 3-4 weeks to see how app is working and address issues.
- Ongoing technical support by email/phone with team as needed.