

# INNOVATIVE MOBILE AND WEB APPS TO CAPTURE EXPERIENCES OF YOUTH MENTAL HEALTH SERVICES:

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## myEXP App

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Inspiring Innovation and Discovery



# Experience-Based Co-Design (EBCD)

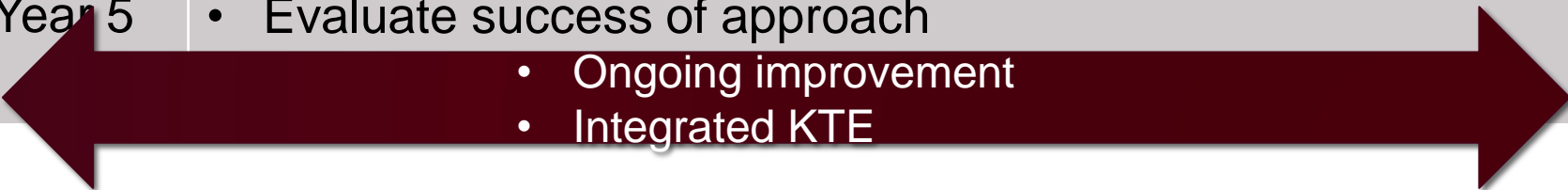
- Policy makers increasingly call for user involvement in health care decision-making and in systems design.
- EBCD<sup>1,2</sup> is one approach that is rooted in the design sciences
  1. Identify ‘touch points’ in experiences
    - Often retrospective, in-depth interviews
  2. Key stakeholders work together to co-design solutions
- **Questions:**
  1. Can we use **real time data-gathering** through use of a smart phone app to engage young people in EBCD?
  2. What are the **key considerations in developing such apps?**

<sup>1</sup>Bate &Robert (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care*. 15(5):307-310.

<sup>2</sup>Mulvale et al. (2016) Applying experience-based co-design with vulnerable populations: Lessons from a systematic review of methods to involve patients, families and service providers in child and youth mental health service improvement. *Patient Experience Journal*, 3(1):117-129.

# Overview of Overall Study

|        |  |
|--------|--|
| Year 1 | <ul style="list-style-type: none"><li>• Develop smart phone app for Youth</li><li>• Web-based application for family members/service providers</li><li>• Pilot apps – COMPLETE</li></ul>   |
| Year 2 | <ul style="list-style-type: none"><li>• Begin recruitment – COMPLETE (12 triads of youth, family member, service provider)</li><li>• Monitor and collect data for 1 year for each case - ONGOING</li><li>• Analyze to identify ‘touch points’ - UNDERWAY</li></ul> |
| Year 3 | <ul style="list-style-type: none"><li>• Host co-design dialogues (youth, family, service provider)</li></ul>   |
| Year 4 | <ul style="list-style-type: none"><li>• Identify policy barriers/facilitators, implementation framework</li></ul>  |
| Year 5 | <ul style="list-style-type: none"><li>• Evaluate success of approach</li></ul>   |



- Ongoing improvement
- Integrated KTE

# APP DEVELOPMENT PROCESS

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# Understanding the Problem

- Care pathways in CYMH – youth use an array of services<sup>4</sup> and are at risk of falling through the cracks<sup>5</sup>
  - Coordination of care
  - Transitions to adult care
- Domains of experience – Communication, trust, preparedness, information sharing, collaboration, family involvement
- Continuity of care dimensions – arrival, relationship with provider, information sharing, family involvement, care plan<sup>6</sup>

<sup>4</sup>Reid, G., & Belle Brown, J. (2008). Money, Case Complexity and Wait Lists: Perspectives on Problems and Solutions at Children's Mental Health Centers in Ontario. *The Journal of Behavioral Health Services & Research*, 35(3), 334 - 346

<sup>5</sup>Davidson, S., & Cappelli, M. (2011). We've got growing up to do: Transitioning from child and adolescent mental health services to adult mental health services. Ottawa: Ontario Centre of Excellence for Child and Youth Mental Health

<sup>6</sup>Tobon, J. I., Reid, G. J. & Goffin, R. D. (2014). Continuity of care in children's mental health: Development of a measure. *Administration & Policy in Mental Health*, 41, 5: 668-86



# ① IN CAMHS

② Preparing to exit

③ Exit CAMHS

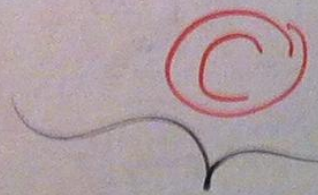
④ Between Services

⑤ Enter AMHS

⑥ Continue AMHS

⑦ Exit AMHS

⑧ Post Exit



- Readiness
- preparedness

④ LAST VISIT

- Readiness
- preparedness

NO CAMHS/AMHS APPT

Weekly prompt no -  
Add "Are you using any other supports/websites?"



LAST VISIT Same as #4  
No CAMHS/AMHS APPT

- Readiness
- Preparedness

- ① Attraction
- ② Entry
- ③ Engagement
- ④ Exit
- ⑤ Extension

## Domain

- Communication \* New word (mutual understand)
- Trust
- Preparedness
- Information sharing (w provider/user vs. among providers)
- Collaboration / joint planning ( " )
- Family involvement
- Development vs. Diagnostic - To what degree are they similar? (continued service plan)

\* Relationship

\* Po T

# Proposed Solution and Features

- Youth are heavy users of smart phone technology
- Fun interface (Fun theory from design literature<sup>7</sup>) and ease of use to keep youth engaged
- What could benefit youth as users but not be an intervention?
  - appointment tracking, online resources
- Attention to stigma and data security issues
- Optimal approach for each user group?
  - Smart phone app for youth and web app for family members and service providers



# Selecting User Preferences

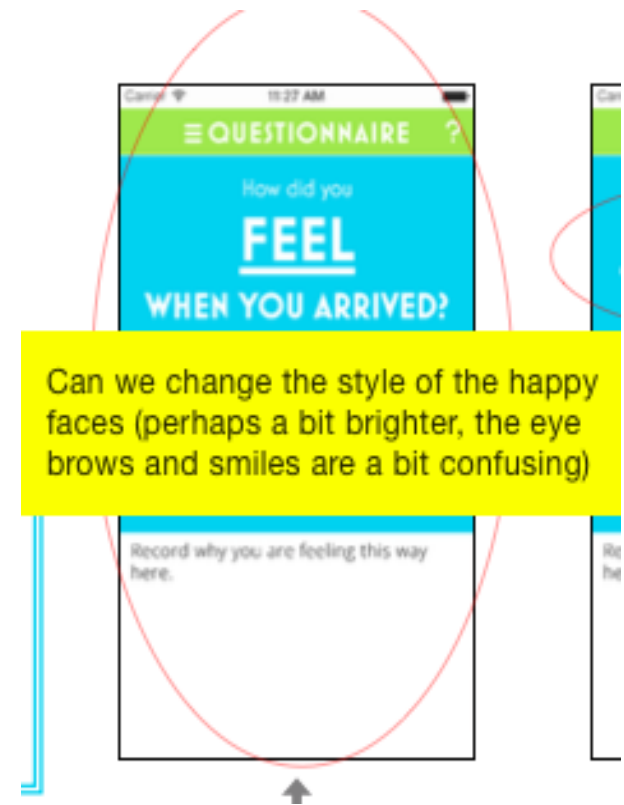
- Questionnaire for appointment experiences
- Easy to navigate
- Quick
- Single question per screen (smart phone app)
- “*MyComments*” – open-ended entries at any time





# Translating Theory into App Features

- Youth friendly, visually engaging, curiosity to continue
  - Language, graphics, colours
- Few screens, brief, neutral questions
- Multiple care pathways, stages to consider
- Must EMPOWER youth as they discuss difficult experiences
- Name is non-stigmatizing, no data stored on device





**INTAKE SURVEY**  
 The intake survey gathers background information on all youth enrolled in the study. It also introduces the youth to the app and the questions they will be asked. The intake survey as one would imagine would only appear once at the first use of the App.

**INTRO**

Our wireframing process follows the user journey mechanism of tracing how a user may be based on the logic identified be faced with a variety of screens from start to finish of a single use.  
 A snapshot of a couple of core functions are shown to highlight the complexity of the App as well as trace the various logical paths for the user based on their responses.

**QUESTIONNAIRE**

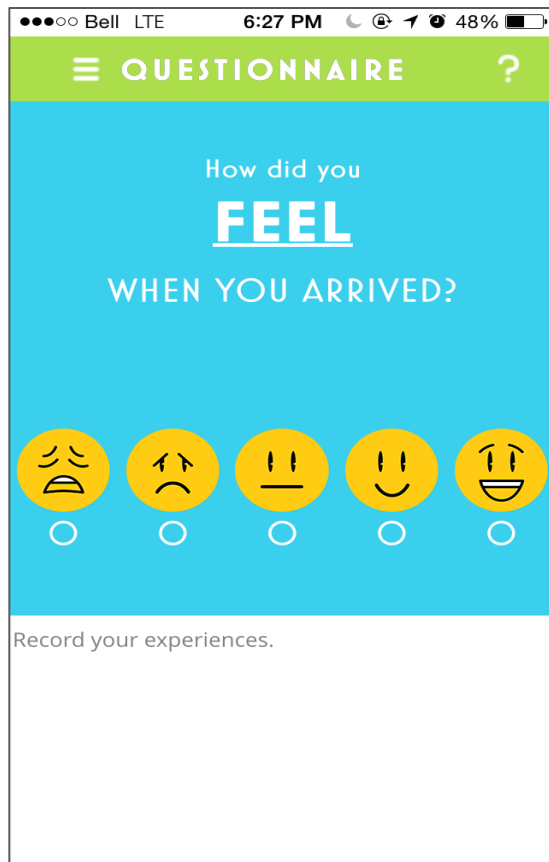
The questionnaire is designed to be delivered following each scheduled appointment. It's goal is to capture the users' subjective experience of an appointment through multiple choice and open ended questions. There are 17 possible questions in the core questionnaire. The 3 possible response sequences are. There is also an exit module that is only answered after the LAST appointment.

# Home Screen



- Formal questionnaire
- Optional comments at any time
- Calendar
- Resources
- Help Screens
- Settings

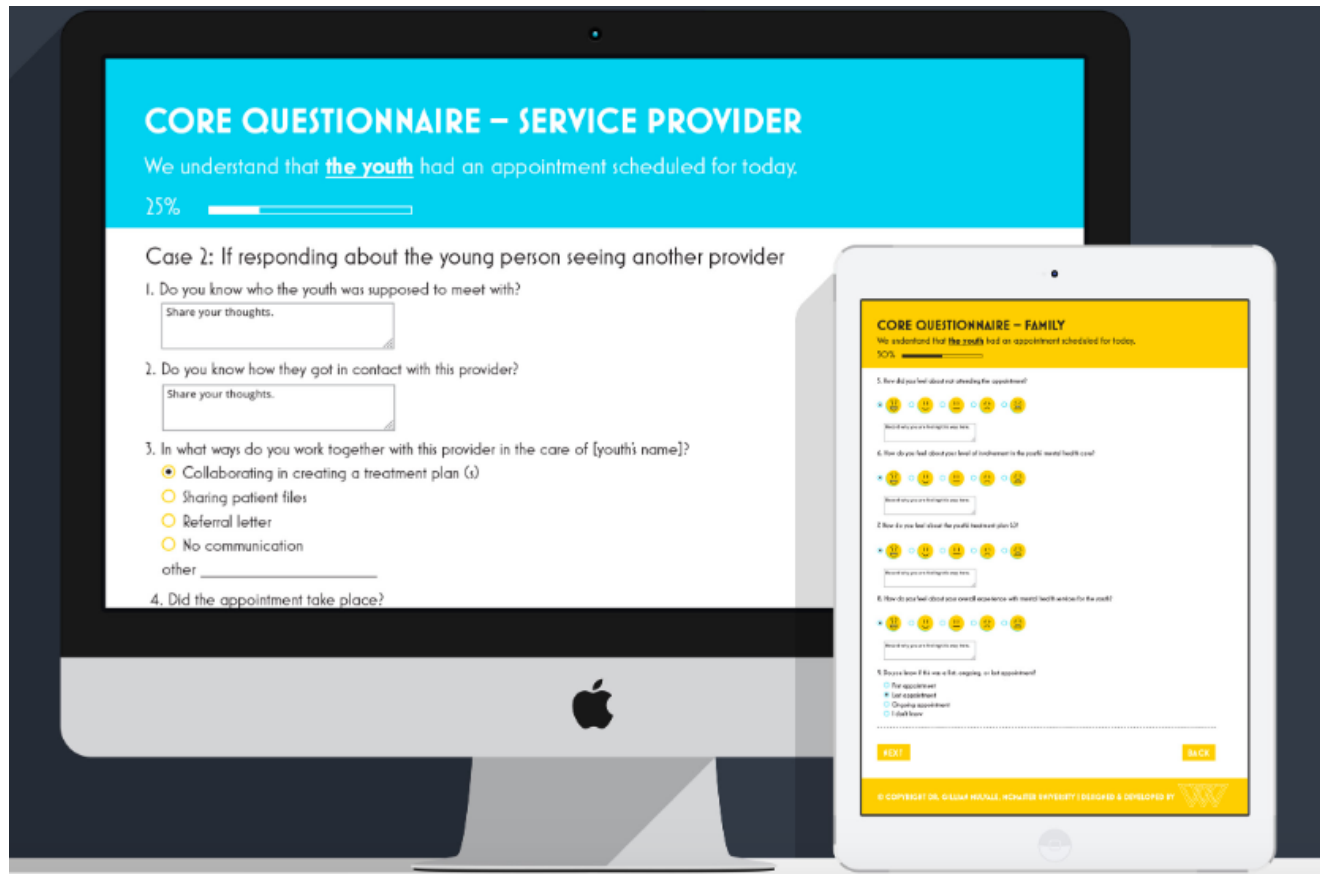
# Data Collection: Smartphone App



- Asks youth about feelings and experiences
- Combination of feelings scale<sup>8</sup> and open-ended questions

<sup>8</sup>Russ, L. R. et al. (2013). Experience-based design for integrating the patient care experience into healthcare improvement: Identifying a set of reliable emotion words. *Healthcare*, 1: 91-99.

# Family & Provider Experiences



# REPORTS PANEL

SECRET  
any

patient name  
provider name  
family member name

# YOUNG ADULTS' REPORTS

PATIENT A

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NEW SEARCH

| APPOINTMENT DATE | PROVIDERS  | QUESTIONNAIRE (YOUNG ADULTS) | JOURNAL (YOUNG ADULTS) | QUESTI (FA |
|------------------|------------|------------------------------|------------------------|------------|
| 2014/07/23       | Provider A | <u>Y</u>                     | <u>Y</u>               |            |
| 2014/07/23       | Provider A | <u>Y</u>                     | <u>Y</u>               |            |
| 2014/07/16       | Provider B | <u>Y</u>                     | N                      |            |
| 2014/07/13       | Provider B | N                            | N                      |            |
| 2014/07/10       | Provider B | <u>Y</u>                     | <u>Y</u>               |            |
| 2014/07/09       | Provider C | <u>Y</u>                     | <u>Y</u>               |            |
| 2014/07/03       | Provider C | <u>Y</u>                     | N                      |            |
| 2014/07/01       | Provider C | N                            | N                      |            |

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NEW SEARCH

# Piloting and Refining the Apps

| Feedback        | Youth  | Family  | Providers   |
|-----------------|--|---|---|
| Liked           | <ul style="list-style-type: none"> <li>• Easy to use</li> <li>• Helpful support</li> <li>• Tracking appointments</li> </ul>      | <ul style="list-style-type: none"> <li>• Calendar function to help youth track appointments</li> </ul>                                    | <ul style="list-style-type: none"> <li>• Quick to complete</li> <li>• Encouraged self-reflection</li> </ul> |
| Mixed Reactions | <ul style="list-style-type: none"> <li>• Calendar</li> <li>• Change 'MyJournal' to 'MyComments'</li> </ul>                       | <ul style="list-style-type: none"> <li>• "How happy was I with youth's appointment, when I don't attend . . . a bit confusing"</li> </ul> |   |
| Recommend       | <ul style="list-style-type: none"> <li>• Adding voice recording option</li> <li>• Ability to see their data over time</li> </ul> |   | <ul style="list-style-type: none"> <li>• Prefer to use a smart phone app</li> </ul>                         |

# EARLY QUALITATIVE FINDINGS FROM APP DATA

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# Youth Feelings:

| About:               |  |
|----------------------|--|
| Upcoming Appointment | “She and I had booked this appointment together, yet I am still <b>very much worried</b> about it and how it will turn out.” (Y3)  |
| The Provider         | “I won't be meeting with doctor (name) for a long time and <b>I'm kind of upset about that.</b> ” (Y2)<br>“ <b>I wouldn't share my feelings</b> with this doctor” (Y4)   |
| Treatment Plan       | “ <b>I don't want to do (treatment type) anymore.</b> ” (Y1)   |
| Exiting a Program    | “it was the last group session so it was a little <b>bittersweet</b> but there's post treatment options and a booster group every month in case you need a little help in the future so I'm <b>feeling pretty good</b> about being able to keep going on my own” (Y7)              |
| Overall Experience   | “ <b>I feel very disappointed with my experiences</b> with (service name). <b>I don't feel heard or trusted</b> by (service name) and I never have even with my eight different ... workers that I've had in the last two years that I've been involved with their services.” (Y6) |

# Family and Service Provider Feelings/Input:

| About:                        |  |
|-------------------------------|--|
| <b>Overall Experience</b>     | “ <b>All right.</b> I would like to better know how the <b>transition to adult care</b> will happen.” (F1) |
| <b>Involvement in Care</b>    | “In there to support but <b>I'm not as involved as I'd like to be.</b> ” (F7)                              |
| <b>Treatment Plan</b>         | “Youth has <b>chosen not to take initiative</b> to follow care plan.” (SP1)                                |
| <b>Additional Information</b> | “Group (type) was over as of yesterday. Next appointment is about checking-in and next steps. (SP3)        |

# LESSONS LEARNED

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# Key Lessons:

1. Engage stakeholders early in the process
  - Researchers, App developers, IT, IP and privacy experts
  - Involve end users early on and use theory to understand preferences
2. Shared goals for researchers and app developers
  - Careful vendor selection is essential
  - Take a **partnership** approach
    - A genuine interest in being involved in research - exploring “things that are not being done”
    - Helps overcome the differences in time horizons for completion
  - Enhances investment of both parties and encourages trust

# Key Lessons (2)

## 3. Open and clear communication

- Address difficult issues early, ongoing feedback
- Challenge each other's use of language and understanding

## 4. Work to keep youth engaged

- App must be engaging to keep the space on device
- Lots of outreach required with this population

## 5. Constraints

- Only one provider in the study for each youth
- Could not use names in questionnaire: de-personalizes
- Existing measurement scales did not align with experience mapping and reflections after each visit

# Final Thoughts

- Technology presents an opportunity to engage youth demographic in mental health research.
  - Less stigmatizing
  - Inherent tension between depth and frequency of data collection
  - Multiple viewpoints on a single encounter
- **Benefits to Research:**
  - Data collection follows the user
  - Opens up the 'black box' of real time experiences
- **Potential for other applications:**
  - Evaluation studies; rapid improvement cycles; informing delivery; other ages/health concerns.

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- We want to acknowledge the wonderful work of our software developers/designers WeUsThem.
- Thanks to the Full Research Team:
  - Ashleigh Miatello, Christina Hackett, Alison Mulvale, Ashwin Kutty, Faten Alshazly

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