



Evaluation Framework for the Adolescent Extended Treatment Centre (AETC)

Final Summary Report for the Mental Health Alcohol and Other Drugs Branch (MHAODB)

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Queensland Centre for Mental Health Research

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List of Abbreviations

AETC	Adolescent Extended Treatment Centre
AMYOS	Assertive Mobile Youth Outreach Service
CHQ HHS	Children's Health Queensland Hospital and Health Service
CIMHA	Consumer Integrated Mental Health Application
CYMHS	Child and Youth Mental Health Service
ED	Emergency Department
HoNOSCA	Health of the Nation's Outcome Scales Child and Adolescent
HHS	Hospital and Health Service
HREC	Human Research Ethics Committee
KPI	Key Performance Indicator
MHAODB	Mental Health Alcohol and Other Drugs Branch
MHEC	Mental Health Establishments Collection
MOS	Model of Service
QCMHR	Queensland Centre for Mental Health Research
QHAPDC	Queensland Hospital Admitted Patient Data Collection
QoL	Quality of Life
RAS-DS	Recovery Assessment Scale – Domains and Stages
RD	Role Description
RSS	Relative Stress Scale
SDQ	Strengths and Difficulties Questionnaire
YES	Your Experience of Service

Executive Summary

The Queensland Centre for Mental Health Research (QCMHR) was engaged by the Department of Health, Mental Health Alcohol and Other Drugs Branch (MHAODB) to develop and support the implementation of an Evaluation Framework for the new Adolescent Extended Treatment Centre (AETC). As part of this process, QCMHR engaged with a wide range of stakeholders to design an Evaluation Framework based on a program logic model to evaluate the activities of the AETC in line with the Adolescent Extended Treatment Model of Service (AET MOS).

The Evaluation Framework and accompanying measurement tools were endorsed by the Advisory Group and MHAODB. Once the Evaluation Framework was finalised, a report was written to provide five recommendations on how to implement the AETC Evaluation Framework.

Over the last nine months, QCMHR has worked with the MHAODB, Children's Health Queensland Hospital and Health Service (CHQ HHS) and external stakeholders to implement these recommendations. This final report is a summary of the progress to support the implementation of the five recommendations endorsed. Seven **considerations** have been identified by QCMHR as foci to ensure the ongoing success of the implementation of the AETC Evaluation Framework over the longer term. Considerations summarised below are discussed in detail in Chapter Three of this report.

- 1. ENSURE CLEAR GOVERNANCE STRUCTURE FOR THE COLLECTION AND REPORTING OF CONSUMER, PROGRAM, AND SYSTEM DATA IDENTIFIED IN THE EVALUATION FRAMEWORK.**
- 2. KEY SUPPORT IS CRITICAL FROM CHQ HHS AETC MANAGEMENT TEAM TO ENSURE COLLECTION AND COLLATION OF DATA OCCURS AS PART OF THE AETC CULTURE.**
- 3. ENSURE THAT THE YOUNG PERSON AND CARER DATA COLLECTED IS PROVIDED TO SERVICES OR PERSONS INVOLVED DURING TRANSITIONS OUT OF THE AETC.**
- 4. THE ID KEY IN REDCAP IS CRITICAL TO TRACKING A YOUNG PERSON AND THE AETC EVALUATION.**
- 5. DATA COLLECTED CAN BE USED TO SUPPORT CLINICAL OUTCOMES AND QUALITY IMPROVEMENT ACTIVITIES.**
- 6. INITIAL AETC SERVICE EVALUATION SHOULD OCCUR AFTER THE FIRST TWO TO THREE YEARS OF DATA COLLECTION.**
- 7. AN ETHICS APPLICATION SHOULD BE COMPLETED ONCE THE AETC IS OPERATIONALISED.**

Chapter 1: Background

The purpose of this final report is to provide the final progress update of activities to support implementation of the Evaluation Framework for the new state-wide Adolescent Extended Treatment Centre (AETC) in Queensland. This is further to the previously endorsed document “*Evaluation Framework for the Adolescent Extended Treatment Centre (AETC): Preliminary Report for the Mental Health Alcohol and Other Drugs Branch (MHAODB)*”. This summary will focus on the progress of preparation for the implementation of the Evaluation Framework throughout 2019 and provide priority considerations for sustaining the implementation of the Evaluation Framework once the AETC is officially operational in 2020.

The Queensland Centre for Mental Health Research (QCMHR) was engaged by the MHAODB to develop an Evaluation Framework specifically for the AETC. The previously endorsed document outlined the completed Evaluation Framework including the context, consultations, and appointed advisory group and expertise involved in its development. Please refer to that document for a comprehensive outline on the development of the Evaluation Framework. This final summary report will refer to decisions outlined in that document, however, is a final update on the QCMHR project as of December 2019.

Key Objectives of the Evaluation Framework

QCMHR were engaged to develop an Evaluation Framework for the AETC to ensure that the new AET Model of Service (MOS) could be evaluated to determine if it met the community needs, partnership opportunities, and any environmental factors that contribute to the outcomes for young people who attend the AETC. The key objectives of the Evaluation Framework were determined across the short-, medium-, and longer-term. These are described below.

Short-term objective: Cohort

In the short-term, the key objective is to ascertain the expected cohort of consumers who will attend the AETC and be most likely to benefit from the AETC’s rehabilitative intervention model. This information supports timely and targeted referrals, providing the greatest opportunity for positive outcomes. Although the AET MOS outlines a description of the likely cohort, it is currently not known who will access the AETC when it is operational.

Medium-term objective: Consumer outcomes

The medium-term objective is to identify consumer outcomes achieved by the AETC. This would include access and opportunities to education and employment, client and family satisfaction with

services, need for acute hospitalisation and crisis care, and comparison of outcomes with other community-based sub-acute and non-acute services.

Long-term objective: Broader outcomes

The long-term objective is to better understand the cohort who attends the AETC and their journey through the health sector. This will support opportunities for earlier intervention and provide cost-effective treatment to reduce the incidence of severe and complex mental illness and subsequent need for extended inpatient care.

To guide these objectives, specific questions were developed to support the selection of measures, key performance indicators (KPIs), and reporting outputs. These can be reviewed in Appendix A.

The Endorsed Evaluation Framework

The endorsed Evaluation Framework (see *Table 1 and Figure 1*) relies on a number of existing systems to collect data, including the Consumer Integrated Mental Health Application (CIMHA), Mental Health Establishments Collection (MHEC), and Queensland Hospital Admitted Patient Data Collection (QHAPDC). Additionally, a new data collection platform will be utilised to ensure that *additional* consumer, carer, and clinician data specific to the outcomes of the AET MOS can be evaluated. Using existing evaluation tools and processes provides an opportunity to build on routinely collected state-wide data and to benchmark and compare existing Queensland sub-acute and non-acute services for adolescents. However, adding in tools that measure the functioning and self-reported measures on quality-of-life and values pertaining to health care, was also deemed critical.

Table 1. Evaluation Framework of the AETC.

Program component	Indicators	Timing	Measure
Inputs	Funding	Annually	Ratio of expenditure to budget.
	Facility	Annually	Bed Occupancy rates
	Qualified staff: <ul style="list-style-type: none"> • Clinical <ul style="list-style-type: none"> ○ support for suitable level of clinical skill in a complex role ○ clinicians with a rehabilitation focus and expertise • Non-clinical • Management • Administration 	Annually	Mental Health Establishments Collection (MHEC) annually
	Referrals / cohort Patterns	Updated Weekly	Complete separate data based (refer to Appendix C)
Activities	Care planning	Collected at intake, during service delivery, and at discharge, reviewed monthly	Refer to instrument section in Appendix C
	Physical assessments	Intake and at agreed intervals in care plan	Refer to instrument section in Appendix C
	Individualised treatment plans and therapy	Collected weekly and reviewed monthly	Type and frequency compared to benchmark defined in care plan
			Consumer satisfaction on treatment received
Clinician rated consumer engagement			
KPIs around Multidisciplinary review and collaborative treatment focus to support rehabilitation orientated culture and therapy planning			
Outputs	Consumer seclusion and restraint	Monthly	Monthly rates are compared to those reported for similar services and to the national target of 0.
	Discharge/transition planning	Monthly	Identification of discharge planning in initial care plan, and at case reviews. Comparison with what is defined in Model of Care Developed KPIs
	Program evaluation and review	Annually	Evaluation report to describe service operations and impacts, including for consumers function, carers experiences and staff milieu and functioning.
Outputs	Throughput of adolescents staying in the AETC	Annually	Evaluation report templates to be developed with the Clinical Systems, Collections and Performance Unit.

	Amount spent per patient	Annually	In addition to direct dollar cost calculations (averaged) looking at a benchmarking for other sub-acute service elements using the SDQ
	Time in AETC	Annually	Number of bed days per adolescent
	Rehab MOS being utilised	Monthly	KPIs established to look at multidisciplinary case-mix, therapy services offered and frequency
	Joint planning between Health and Education	Monthly	KPI looking at evidence of joint weekly meetings and joint PSP (personalised support plans) for each adolescent.
	Smooth transition from AETC	Annually	KPI to be developed
Consumer outcomes	Reduced risk of suicide and self-harm	Intake, discharge and 1-year post-discharge*	Measures may include number of suicide attempts and occasions of self-harm.
	Improved mental health and social functioning	Intake, discharge and 1-year post-discharge*	Refer to selection of instruments (Appendix C)
	Improved engagement with education and employment	Intake, discharge and 1-year post-discharge*	Refer to selection of instruments Appendix C
	Improved relationships	Intake, discharge and 1-year post-discharge*	Refer to selection of instruments Appendix C
	Reduced hospitalization and crisis care*	1-year pre-intake and post-discharge	Look to link data sets via CIMHA and state-wide reporting
Program outcomes	Partnerships with other MH services support continuity of care	Annually	Evidence of follow-up communication with referrers upon intake and discharge and in the case of unsuccessful referral. Survey of referrers, external service providers, consumers and carers on views of referral pathways and continuity of care.
	Interagency partnerships support wraparound care	Intake, discharge	Evidence of shared care plans (including consent to share information) with referrers and community services at intake and following discharge.
	Consumers and carers are satisfied with the service	Intake, discharge and Annually (YES survey run by the MHAODB)	Refer to selection of instruments (Appendix C) Use of YES survey
	Program is aligned with service model/ program fidelity	Annually	Adherence to program principles e.g. Rehabilitation and Health/ Education integration CIMHA activity on Multidisciplinary team activity and developed KPIs
	Assaults on staff	Monthly	Monthly assault rates are compared to those reported by other health services and a target rate of 0.
	Staff are satisfied with the service and work environment	Annually	Internal staff interviews, focus groups and rates of staff turnover and sick leave may provide insight into satisfaction and risk of burnout.

	Culture and workplace integration suitable to a rehabilitation MOS		Staff surveys on workplace culture to be implemented annually.
	Allocated funding is aligned with actual service costs*	Annually	Allocated funding is compared to actual costs including evaluation activities.
	Cost effectiveness. Program reduces burden on acute MH services and associated costs*	Annually	Benchmarking with other sub-acute service elements using HoNOSCA adjusted for QoL
System outcomes	Better understanding of Appropriate access to extended youth mental health services	Annually	Benchmarking with other Sub-Acute service elements.

Figure 1: A diagrammatic representation of the evaluation framework.



Chapter 2: Implementation of the Evaluation Framework

The final six months of QCMHR involvement in this project has focused on supporting preparation for implementation of the AETC Evaluation Framework recommendations identified. Progress on this is provided below, along with further considerations.

Original Recommendations for the Implementation of the Evaluation Framework

When the Evaluation Framework was completed a number of recommendations around its successful implementation were identified. A summary of the broad recommendations is listed below, while *Appendix B* provides more detail.

- **RECOMMENDATION 1: ENSURE HIGH-LEVEL SUPPORT FOR AETC EVALUATION FRAMEWORK AND IMPLEMENTATION.**
- **RECOMMENDATION 2: DEVELOP A SIMPLE SET OF CONCRETE MEASURES THAT ARE FEASIBLE TO COLLECT THE DATA DURING IMPLEMENTATION.**
- **RECOMMENDATION 3: EXPLORE OPTIONS FOR SOFTWARE SPECIFIC TO AETC DATA COLLECTION AND OTHER SUB-ACUTE SERVICES.**
- **RECOMMENDATION 4: IMPLEMENT THE EVALUATION FRAMEWORK.**
- **RECOMMENDATION 5: COLLECT AND ANALYSE DATA BASED ON COHORTS OF CLIENTS WHO ATTENDED THE AETC.**

Progress of the Implementation of these Recommendations

A consistent strength of this project has been the enthusiasm and dedication of all stakeholders involved to ensure that the AETC Evaluation Framework receives the investment, expertise, and priority required to ensure its success. Progress of development of the Evaluation Framework ready for handover and implementation has required cooperation and clear governance structures with all key stakeholders across MHAODB (system manager/ project sponsor) and Children's Health Queensland Hospital and Health Service (CHQ HHS) (operational lead). Regular meetings with all key stakeholders to progress implementation of the interim report and Evaluation Framework recommendations have occurred during the past six months. As of writing this report, **RECOMMENDATION 1** has been met.

To support **RECOMMENDATION 2**, the Advisory Group for the Evaluation Framework of the AETC discussed numerous carefully selected measurement tools and decided on their inclusion or exclusion based on careful consideration and balance of five parameters extensively outlined in the

[first report](#). These tools have been trialed and tested across young consumers, carers, and clinicians and are reported on, separately, later in this document.

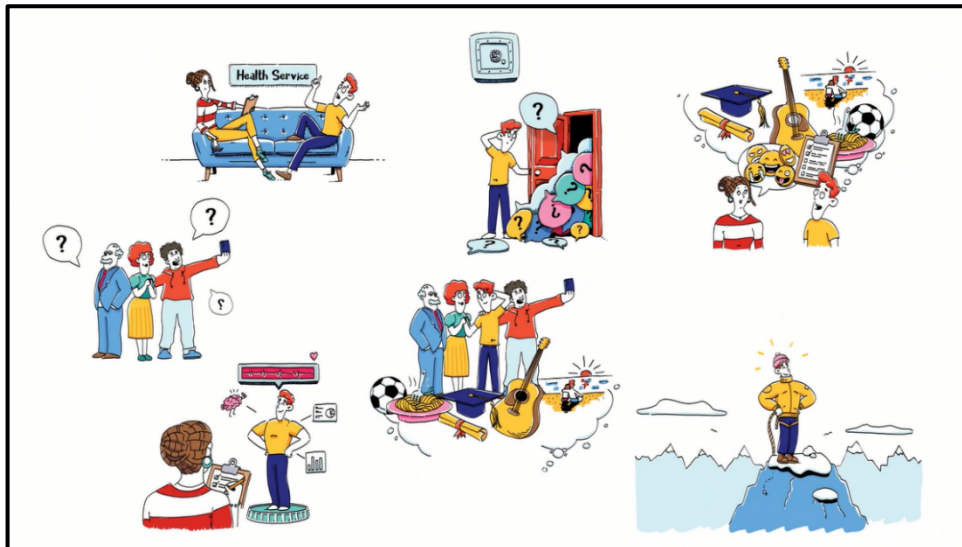
The MHAODB, with consultation from the Advisory Group for the Evaluation Framework, supported the utilisation of an electronic platform to collect additional data from consumers, carers and clinicians as part of **RECOMMENDATION 3**. A purpose built secure electronic data capture platform (i.e. RedCap) offers a way to ensure efficient data collection. Paper and pen surveys were considered unsuitable for this target group and more likely to result in collection and input error. The decision to trial the use the electronic data collection platform *RedCap housed at CHQ HHS* was made based on the following reasons:

- Feasibility - cost and ongoing ethics conditions were the principal reason behind the selection of RedCap as an initial platform ;
- A secure network that would be based within a Queensland Health firewall for security and confidentiality of data;
- A platform that has no cost and is already utilised across a number of HHS;
- Ability for ease of analysis/research to be conducted in the future

Ongoing partnership and support from The Clinical System, Collections and Performance Unit within the MHAODB has been critical to support this, as the AETC will be a state-wide service and the *addition* of an electronic data collection platform needs to support the suite of clinical records already collected.

RECOMMENDATION 4 involved a number of components that would enable best practice and support for the implementation of the Evaluation Framework. This included the need to communicate with the young person and their family why their data is collected, as well as supporting clinicians to implement and actively engage in a thorough evaluation of the service.

A video has been developed and funded by QCMHR in consultation with a CHQ HHS youth consumers and the AETC Evaluation Framework Advisory Group consumer representative. This brief educational video was designed to inform young people about why data is collected, confidentiality, and what happens to their data in the longer-term. The completed video can be viewed at https://f.io/aS-t1G_5, where the end frame can double as a handout to the consumer (see image below).



This link can be hosted at a number of sites including MHAODB, QCMHR, and on the electronic platform of CHQ HHS for access by young people and their families. The video was developed by QCMHR with the aim to show a young person and their family attending the AETC *prior* to the completion of measures. However, it also has broader utility to communicate to any young person why information is collected across all areas and services of CYMHS.

A training PowerPoint has been developed to orientate staff of the AETC to the Evaluation Framework. This educational PowerPoint (with vocal guidance) aims to ensure that the gap between QCMHR project completion and the operational opening of the AETC are as least disruptive as possible. A risk with QCMHR finishing earlier than the opening of the AETC is that the knowledge and integrity of the Evaluation Framework may not be implemented. This training PowerPoint offers context to new staff about how the measurement tools were selected as well as *how* to use the RedCap collection platform.

Meetings between MHAODB, QCMHR, and CHQ HHS, for the development of business rules and processes for data communication have been occurring over the past six months. Chapter 3 will identify that a priority of a clear governance structure for the collection and reporting of all data collected as part of the AETC evaluation is required. MHAODB, QCMHR, and CHQ HHS jointly supported that the Evaluation Framework endorsed and implemented occurs for a period of 2- 3 years initially to support **RECOMMENDATION 5**. This timeframe was seen as a good balance between ensuring that:

- 1) Adequate collection of data to complete a meaningful analysis can be achieved,
- 2) Testing a new data collection system with young people and carers can occur with a good sample size on a 'new system',
- 3) Outcomes related to the AETC MOS delivery can be reviewed after a relatively

short period of time to ensure that the service is operating as per the MOS.

It is recommended that an external evaluation occur at the conclusion of this Evaluation Pilot to provide recommendations and considerations for the longer-term implementation of the evaluation framework, including benchmarking against other Adolescent Extended Treatment (AET) services.

Trial of Electronic Platform to collect Consumer, Carer, and Clinician data

A trial of the data collection was completed over six weeks from 22 July to 30 August 2019. The trial involved accessing young people, carers, and current CHQ HHS clinicians (AMYOS, Day Programs North and South) and the Inpatient Unit to test the data collection system. An author of this report visited one of these sites weekly to ask for participation. Young people and their families were very happy to participate if they were at the service on those days. Two main objectives were the focus of this testing period.

- Firstly – the acceptability of the survey, e.g. how long it takes to complete, any ambiguous questions that may need rewording, questions that don't work (such as logic branches within the survey) from the young person, carer, and clinician perspectives.
- Secondly – how the data is presented in RedCap and designing dashboards that can be utilised for overall (i) evaluation of the AETC, (ii) communication to the MHAODB regarding the AETC, (iii) to use in ongoing quality activities, and (iv) support the communication of young person and carer data.

A total of six surveys were designed and tested:

- Young person (a purple survey for both **pre and post**),
- Carer(s) (a yellow survey for both **pre and post**)
- Clinician (a green survey for both **pre and post**)

Full copies of these survey can be reviewed in *Appendix D* with examples of the front page of each survey looking like this;

The image displays three screenshots of survey forms. The first is a purple-themed 'Consumer (Pre)' form with a group of diverse people illustration. It includes a 'Thank you!' message and a list of questions: 1) Consumer code (text input), 2) Date of Birth (date picker), and 3) Gender (radio buttons for Female, Male, Transgender/ female, Transgender/ male, Gender variant/nonconforming, and Prefer not to answer). The second is a yellow-themed 'Carer Post' form with a family illustration. It includes a 'Thank you!' message and a list of questions: 1) Consumer code (text input). The third is a green-themed 'Clinician (Pre)' form with a group of people illustration. It includes a 'Thank you!' message and a list of questions: Consumer code (text input), Date (date picker), Date of birth (date picker), Age (text input), AETC Clinician (text input), Suburb (text input), and Currently under TA (radio buttons for Yes/No).

Young Person, Carer and Clinician Feedback

The following were the questions that guided the feedback:

1. Can the platform be accessed easily via a link (either on an iPad or Queensland Health computer?)
2. How long does it take each group (young person, carer, clinician) to complete the survey?
3. Can they navigate and understand the questions being asked?
4. How can the outcomes from measures be presented to provide (i) feedback to the young person/carers, (ii) have utility by the clinical team to review functioning and goals of young people and (iii) ensure the overall evaluation of the AETC is being completed and communicated?

Using these questions as a guide, the following general feedback was provided. Table 2 shows feedback from consumers and carers, while Table 3 shows combined feedback from clinicians.

Table 2. Consumer and Carer RedCap Survey Feedback.

Number	Date	Type	Time	Comments/notes
1	24/7/19	YP	6:00	
2	24/7/19	YP	7:00	Nothing
3	24/7/19	YP	6:00	Easy
4	24/7/19	YP	5:00	Make sure the scales are the same way around e.g. Rarely, sometimes, never are consistent all the way through
5	15/8/19	Carer	7:00	Easy to follow, relevant to service. - Looked like he put the wrong "consumer code" in
6	15/8/19	Carer	7:14	Doesn't like surveys in general. Didn't like that the categories had "hard" answers (categories). Would prefer if there were comment boxes for some of the questions.
7	15/8/19	YP	5:00	Liked how quick it was, and it was easy to understand
8	15/8/19	Carer	3:49	Easy to follow, just didn't like the categories for the first surveys – didn't "fit" with the actual questions (SCORE-15)
9	15/8/19	YP	7:47	Liked the variety of questions, liked that all the questions were split into different pages, liked the different rating scales and that they weren't all the same.
10	15/8/19	YP	13:00	Gave feedback as we were going, so the time was a lot higher. Overall, he found it more difficult to answer some of the questions that were "vague". As someone with Asperger's he doesn't know how to answer these questions. He would have preferred some of the questions to just ask what they were asking i.e. be more specific. He also commented that people with anxiety might also find these "vague" questions difficult as it would make them anxious about whether they are answering the right questions "correctly" for example. - Q.5 wording, make it more "plain" language if possible - Q.7 "I was allowed to make..." - Q.8 no space between the words - Q.16 - Q34 "notice" not identify? - Q.35 - Q36. Feel better – not "unwanted symptoms" - Q.40
11	15/8/19	Carer	5:17	Some of the questions didn't really fit the categories, especially the SCORE-15 categories – he thought they would have been better suited to the "strongly agree, agree..." style categories of the contextual outcomes surveys. - Q.2 of SCORE-15 is a double negative (not sure if we can change this) - Q.24 "How much" – grammatically incorrect(?) – again fitting these into the categories doesn't always work
12	15/8/19	Carer	6:14	[Actually read all of the instructions] - Q.38 no spaces between the words (need to fix this)

				Some of the questions don't always fit in the categories e.g. "we don't bring DP stuff home but we do implement the strategies" – related to talking about stuff in my family question. Could be yes, could be no
13	15/8/19	Carer	5:15	Categories of SCORE-15 don't fit the questions. Headings don't fit on the page i.e. for SCORE-15 when you get to the last question, you can't see the categories at the top Q. 15 typo – needs to be "new ways" Have to do a lot of surveys in CYMHS, so make it as simple/easy as possible. Liked the length of the survey.
14	15/8/19	YP	3:20	Easy to understand, short. Maybe have a comments section at the end if there was any other feedback about the service the young person might want to give (that didn't fit in the other boxes) [was very quick as he didn't actually answer the questions correctly, was just looking at the wording/grammar etc.]
15	15/8/19	YP	5:14	Nothing
16	15/8/19	YP	12:37	Took a bit longer as he read everything in depth, didn't have any feedback though
17	22/8/19	Carer	3:29	Easy to follow [typed the consumer code in wrong]
18	29/8/19	YP	3:34	Easy to follow, wouldn't add anything
19	29/8/19	YP	2:30	Nothing
20	29/8/19	YP	7:27	Nothing
21	29/8/19	YP	4:04	DP - Easy to understand and read, liked it. Wouldn't add anything else. Got the consumer code wrong and DOB wrong (although I think they read it correctly)

Table 3. Clinician RedCap Survey Feedback.

Survey	Clinician comments/notes
Pre-survey	<p><i>General comments both verbally and in writing reported that the survey was very easy to read and use and that the data dictionary and prompts were helpful.</i></p> <p>Specific Feedback</p> <ul style="list-style-type: none"> • The question which asks how often has the young person not wanted to attend – I think this is too ambiguous because it is measuring a state of mind – you would be better to state 'failed to attend'. These questions also don't capture school reluctance which manifests itself as leaving early – but not sure whether you want to capture this also • The questions which state 'these problems' referencing reason for not attending school – there is no reference point for what is meant by 'these problems' – I'm assuming you mean 'mental health issues/difficulties'. Young people also don't attend school because of family chaos, lack of transport etc, so will need to be more explicit in the cause you are asking the clinician to measure • Family structure question – I would have imagined it was important to measure statutory out of home care separately from family arrangements (for feedback to Child Safety regarding numbers of cross-over kids), these definitions also don't sound like they're a great fit for indigenous kids and the term 'intact' family might need defining • History of custody – in a mental health setting this term isn't used that frequently (unless you work in forensic services) and it would be important to specify you mean the young person and not their parents eg Has the young person spent time incarcerated previously? • The questions quantifying education attendance, are you wishing to measure simply total attendance, or would you prefer to measure proportion of attendance compared to scheduled program? Young people often leave programs such as these with a planned part-time education timetable – it may be better to say something like 'How often did the young person attend their planned education/vocation program?' – useful also to substitute school for education/vocation if you're wanting to measure more broadly than just school attendance. Many young people will be working towards TAFE, other education or vocation rather than school during their time at AETC. • Other services involved – term 'disability service', do you mean NDIS provider? • Term 'rehabilitation program' – the term rehab isn't used much in a mental health setting and has connotations to drug and alcohol treatment (although I respect this may be the term they are going with for this program) – the term recovery is more consumer-friendly. The term 'program' isn't usually used to describe individual provisions of service which what this question appears to be trying to capture. You will need to define what a 'program' is for this question (ie. Individual session, group session etc) – I would imagine describing them as 'recovery sessions' may be a better fit (although if you want to match with CIMHA language you could consider provision of service). The term 'further education' is also ambiguous – not sure what we would be measuring here.

	<ul style="list-style-type: none"> • The term 'recurrent self-harm' is used in both surveys, I think recurrent is redundant and confusing as you are then asking for a frequency rating, it is unclear whether you are only rating self-harm which occurs more than once in an episode • Term 'Rehabilitation goals' – I think 'recovery goals' fits with current mental health language better • Some questions could be more clearly defined. E.g. Suburb at referral? It would be helpful if it said something about it being the Consumer's address. • The part that asks for DOB of client – remove the "today" button function as I think people may tend to click this which would jump to today's date. • It may be useful to have categories to break up the information being asked. Or if not categories, different pages/sections of the survey that indicate a different category of information. E.g. breaking it up in sections such as Demographics, Mental Health History, Physical Health • Have BMI automatically calculated once weight and height are input. As calculating this takes extra time. • Have a N/A option for some of the questions otherwise it might confuse the user as to whether they leave the boxes unticked e.g. Culture question • With the diagnosis do you want people to put in the codes as well as names? • Does secondary mean F codes or does it include z codes
Post-survey	<ul style="list-style-type: none"> • Breaking up survey with headings/sections/pages • Age could be auto-populated as DOB is already answered in previous question • Again, have BMI auto-calculated as this adds extra time to survey • Education/Vocation section – have paid employment, volunteer work as options • Question could be defined more clearly, asking to quantify – e.g. How many times has the consumer attended recovery sessions in the past 4 weeks? • Last question about YP being able to complete their recovery goals is a bit ambiguous • Should there be an option for "declined further service" as reason for transfer of care or is this under "unplanned closure" • Clear definitions re what the recovery sessions mean like "skills training" • How often was young person able to complete recovery goals – I feel this is a bit hard to answer as some goals are long term, have multiple parts, it may not be a simple yes or no that goal was completed in order to be counted.

Developing Dashboards

From the feedback gathered from the survey testing, modifications were made to a number of the questions as well as the overall look of the survey. Some of the feedback from clinicians was not possible to incorporate – such as having the survey calculate the body mass index (BMI) – as this is not a function that can be utilised in RedCap. Other issues around how to answer the questions will be placed into the data dictionary and be addressed via training and through ongoing fidelity discussions once the AETC team is fully established. From here, example dashboards were created to show how the results from the survey could be used in a simple, visual format. *Figure 2* shows an *example* of what the clinician dashboard would look like for the information input by clinicians as consumers enter the AETC service. *Figure 3* is an *example* of the consumer dashboard as they leave the AETC service, and *Figure 4* shows an *example* of the carer dashboard as their young person leaves the service.

Figure 2. Example AETC Clinician (pre) Dashboard.



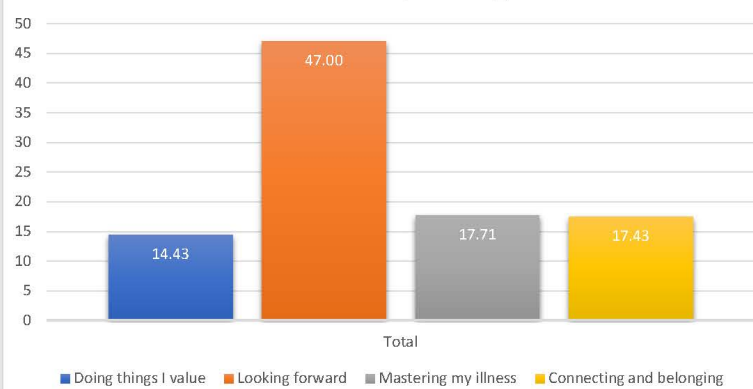
Figure 3. Example AETC Consumer (post) Dashboard.

Consumer RAS-DS Data (post)



Note: the higher the RAS-DS score, the better the consumers feel about their recovery process i.e. higher ratings mean recovery areas the consumer feels more positive about.

RAS-DS Group Averages



Value Based Healthcare Questions

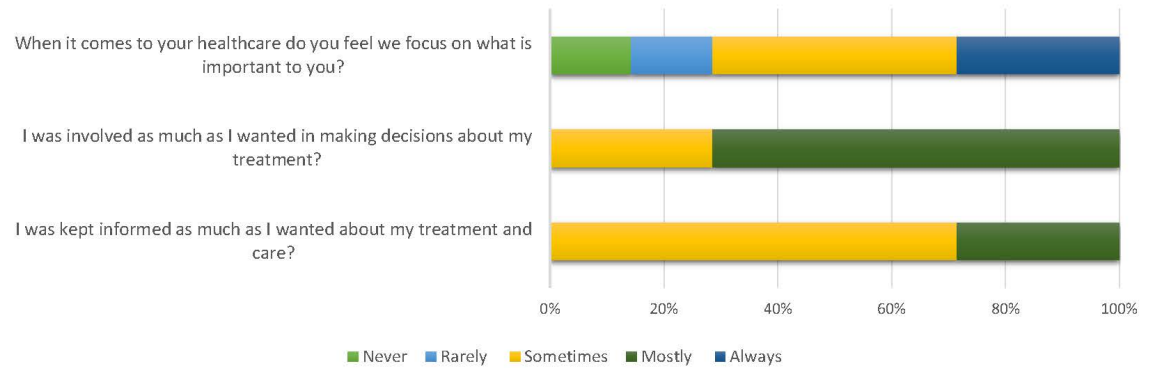
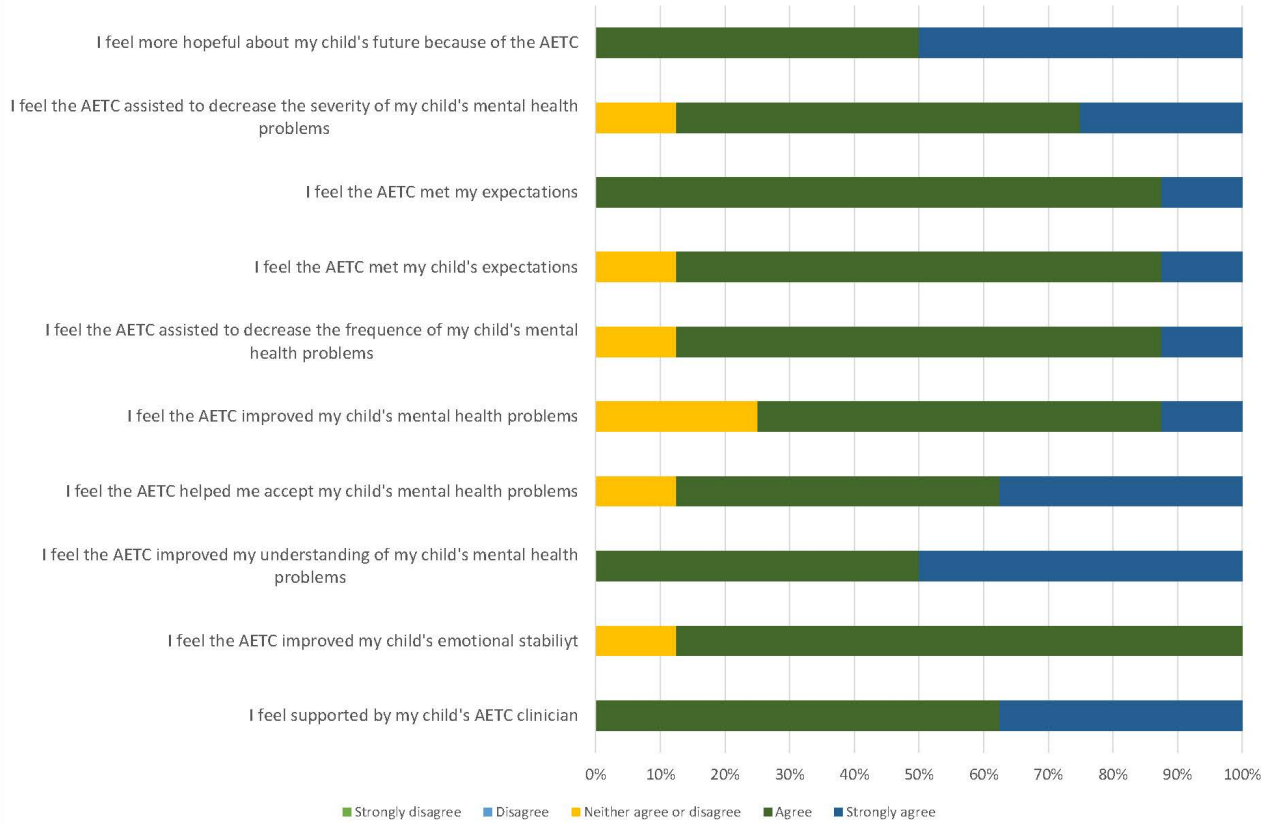


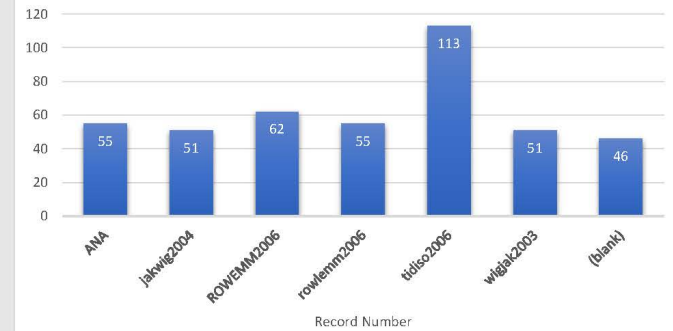
Figure 4. Example AETC Carer (post) Dashboard.

AETC Carer (post) Results

Parent/Carer Contextual Outcomes Survey Results

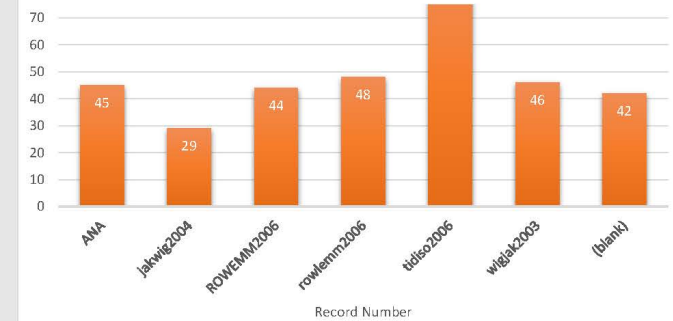


Carer Post Total SCORE-15 Scores



Note: the higher the result, the better functioning a family member reports.

Carer Post Total RSS Score



Note: the higher the numerical result, the more stressed the carer is reporting.

Consumer Code

In order to track and match the data of the consumer from a clinician, carer, and self-rating all together, there needs to be a way to link the consumer to the clinician and carer data related to them. While testing the online surveys, it became clear that the consumer code errors were high from both the young person and their parent/carer. Errors relating to mixing up first and last name and even having the wrong date of birth were commonly found. As the consumer code is a critical link of the consumer outcomes of the evaluation, it is recommended that the **AETC clinician** completes this consumer code for the young person and carer before they complete the survey (*Chapter 3 will address this consumer code in more detail*).

Chapter 3: Further Considerations / Recommendations for Managing Evaluation once the AETC is Operational.

The QCMHR project team that has developed and supported implementation of the AETC Evaluation Framework will finish, as per the original project agreement, in December 2019, while the opening of the AETC will not occur until early 2020. QCMHR have completed the agreed scope of the project, and communication and handover of this project to our key stakeholders has occurred.

QCMHR would highlight some further priority considerations that are imperative for the sustainability and overall effectiveness of the Evaluation Framework in the short- and longer-term.

Consideration 1.0

Ensure clear governance structure for the collection and reporting of consumer, program, and system data identified in the Evaluation Framework.

As the AETC is a state-wide service being operationalised by CHQ HHS there is a risk that the Evaluation Framework data to be collected as part of operations and delivery of the Framework loses accountability to the MHAODB. Consideration for the use of a quarterly report to be collated and communicated to the MHAODB is highly recommended. This report would need to ensure that consumer, program, and system data identified is being routinely collected and all linked. The developed dashboards from RedCap could be collated along with important CIMHA data and routine inpatient KPIs that address the program and system data and presented yearly to ensure the AETC Evaluation is kept on track. Clear processes outlining how the data collected by CHQ HHS is collated and disseminated to the MHAODB needs to be developed. Options around both CHQ HHS and MHAODB having access to the same SharePoint should be considered, or alternatively a process where data is collected, collated and then presented from CHQ HHS to a governance meeting facilitated by the MHAODB. QCMHR will ensure that access and orientation to RedCap administration will be given to critical staff at both CHQ HHS and MHAODB. Copies of the Excel template to populate the RedCap dashboards will also be provided to all key administrators.

It is important to note that the collected RedCap data is an *additional data* collection expected to be done by staff within the AETC, as well as from young people and their carer(s). It should not, at any stage, undermine the integrity of the suite of clinical records already collected (e.g. CIMHA). At times, this will result in some duplication of data which, at the end of the pilot evaluation period, can be reviewed to see (a) what changes or additions have occurred within CIMHA, (b) what measurement tools are being collected, and (c) if duplications are no longer required due to

changes in practices/process or a clearer understanding of the AETC outcomes and cohort. For example, the selected AETC drug and alcohol measure was chosen by the Advisory Group as it has the ability to compare to already collected information from other AET services. However, since that decision was made, CIMHA has now included the AUDIT tool into the clinical records which, once utilised routinely across all services, may supersede the need for the drug and alcohol tool within the AETC *additional* suite of measures.

Part of the statewide MOS for the AETC involves an intake panel for referrals of young people across the state into the AETC. Records and data keeping of the intake panel outcomes needs to be considered for the evaluation of the short-term outcome of determining the cohort that the AETC best services. Data on all young people that are referred to the AETC, regardless of if they are accepted into the AETC or not, needs to be collected and included in a governance meeting.

CONSIDERATION 1.0 – It is essential that data collected on the consumer outcomes, program outcomes, and system outcomes throughout the pilot evaluation period are communicated in a timely, consistent, and collated manner. This data could be presented at a governance meeting held each quarter between the MHAODB and CHQ HHS, and relevant stakeholders to present output and updates across the three key areas of evaluations. This will ensure that there is no disruption to the data already collected through CIMHA but also include the additional measures that are to be reviewed by both CHQ HHS and MHAODB.

Consideration 2.0

Key support is critical from CHQ AETC Management team to ensure collection and collation of data occurs as part of the AETC culture.

In order for the evaluation to be successful the data must be collected, cleaned, and communicated. Whilst significant and successful consultations have occurred as part of the implementation of the Evaluation Framework, an overall risk is that without support from leadership, reliable data may not be routinely collected. Though business rules have been developed to ensure the timely and accurate collection of data by AETC staff, a culture that is proactive and engaged in evaluation and research is critical to its success. Creating a culture where data is valued and seen as a tool to assist with excellent quality care is essential, all of which needs to be championed by leadership.

The Evaluation Framework has been developed based on the ability to utilise **both** CIMHA and RedCap data, and on the basis that both are completed accurately as a mandatory part

of core business at the AETC. For example, in order to look at the overall health economics of the AETC it was suggested by the AETC Advisory Group health economist that CIMHA tool, the Strengths and Difficulties Questionnaire (SDQ), can be 'cross-walked' with the Assessment Quality of Life (AQoL) to assess health-related quality of life, which can then be used to look at economic utility of services in evaluation. It was decided that this would be a better way to investigate the health economics related to the service rather than add an additional measure to the RedCap collection. It is imperative that the SDQ is completed 100% of the time at the AETC, so that appropriate economic evaluation can occur.

A member of staff or a research officer with expertise in data management should be considered in the recruited staff skill-mix. Having a staff member who is able to support the AETC's data collection is imperative. Whilst every effort has been made to ensure the RedCap pilot tool is as easy to use as possible (in context to not being able to purpose build an expensive IT system), there will be a need for a staff member to develop skills in using RedCap to maximise its utility. It is suggested that the senior management of the AETC and MHAODB, as well as an identified staff member with experience, holds access to the 'back-end' of RedCap and can access the data as required for specific reason(s) (e.g. a young person wants to look at their start/ end change while at the AETC).

CONSIDERATION 2.0 – The Evaluation Framework is built on collecting CIMHA, RedCap, and standard health processes data. It is critical that all of these outcomes are collected, checked, and reported on routinely as per recommendations in Consideration 1.0.

Consideration 3.0

Ensure that the young person and carer data collected is provided to services or persons involved during transitions out of the AETC.

Feedback from both young consumers and carers voiced the importance of data collected being available for future services providing care to the young person. The data collected at the AETC has a great emphasis on the young person's self-report of functioning and recovery as well as carers' well-being and perspective on supporting their young person. It is recommended that a summary of this information is provided in a written handover for ongoing care following the end of the young person's AETC stay. Whilst the data is being collected for an overall evaluation of the AETC service, its utility to support communication across all areas of care for a young person is critical.

The RedCap dashboards can be used as a way to summarise this data. However, this becomes more challenging for clinical teams without research support or a member of staff who is not able to collate data using RedCap and support the interpretation of it.

CONSIDERATION 3.0 – Ensure that transfer of care documents include a summary of RedCap data. This is a summary of the young person’s self-report of functioning and recovery as well as carers’ well-being and their view on how to support their young person. It is essential that a staff member within the AETC should have knowledge on how to do this.

Consideration 4.0

The ID Key in RedCap is critical to tracking a young person

The young person and carer survey will be run on an iPad. In order to identify who has completed a survey and then link that young person to their carer and the clinician information there are two main options to consider.

- 1) The survey could be set up for every young person and their carer(s) via the ‘backend’ of RedCap by putting in an email specific to that young person/carers. This would then send out a survey link out via their email address. At the end of the survey you would issue the survey back out through this link. However, this assumes everyone has an email address as well as the ability to access their email on the iPad in order to complete the survey. It also requires a clinician or a Research Assistant to set up the survey when you want to complete it, which increases the number of staff who would need access to the ‘back end’ of RedCap.
- 2) The second (preferred) option, which simplifies the process, is having an individual survey link that can be used on each iPad. A downside to this, however, is that it does not identify who is completing the survey. To overcome this, an **ID Key (consumer code)** has been set up at the start of EVERY survey. This consumer code ensures that each young person has the same ID Key, whether data is being entered by the young person themselves, a clinician, or a carer. This ID Key will be the *first 3 letters of the young person’s surname*, followed by the *first 3 letters of the young person’s first name*, followed by their *month and full year of birth*. For example, the key for Mary Smith born 1st January 2004 would be **SMIMAR012004**. It is crucial that this information is entered at the beginning of every survey by a trained clinician to ensure accuracy for later linking and analysis. As it is a critical link for connecting pre- and post-data across the surveys of the young person, carer(s), and clinician measures, as well as with CIMHA data, it must be entered correctly.

Additionally, an excel spreadsheet list of ALL consumers and their consumer code that attend the AETC must be collated so at the end of the pilot collection period when an independent external evaluation is completed, CIMHA data can be linked to the same young person and their family. This consumer code is **critical** to the evaluation and the ability to link data with other clinical records. A list that is regularly reviewed by both CHQ and MHAODB for accuracy and completion is imperative.

CONSIDERATION 4.0 – The consumer code (ID Key) is a critical link to the data across the young person, carer(s) and clinical surveys. It is strongly recommended that clinicians complete this code and a list of all consumers and their corresponding code is kept and a clear process for recording and accountability for this is embedded into the AETC service.

Consideration 5.0

Data collected can be used to support clinical outcomes and quality improvement activities.

The Evaluation Framework ensures that data collected is critical to the AETC outcomes related to delivering care in line with the MOS. However, the data being collected can also have important additional benefits. Information about the young person's perception of their recovery and functioning is being collected by both the young person and their carer(s). Whilst this information is critical to the overall effectiveness of the AETC as a rehabilitation-oriented service, it offers real time opportunities to inform clinical care to the AETC treating team. Utilising the data via RedCap collection to improve clinical outcomes would be very useful. RedCap can be used to complete any repeats of a measurement tools as required. For example, if mid-way through a young person's admission in the AETC a further Recovery Assessment Scale – Domains and Stages (RAS-DS) was required to review functioning and goals, this could be done. However, a person with knowledge to establish a link correctly would be required (see Consideration 2.0).

CONSIDERATION 5.0 – Ensuring that while the data collected from young people and their carer(s) is critical to the overall AETC evaluation, this data can also be accessed and utilised in clinical care to guide clinical practice.

Consideration 6.0

Initial AETC service evaluation should occur after the first two years of data collection.

Collection and analysis of the evaluation data will be complex. While enough data needs to be collected in order to determine overall effectiveness of the AETC, data also needs to be reviewed regularly to ensure quality processes are monitored and adapted to any changes. It will be important to balance the reporting of data for quality processes/improvements with the ongoing collection of data for evaluation purposes in order to develop longer-term processes based on outcomes of the pilot evaluation period. MHAODB, QCMHR and CHQ HHS jointly supported that at the end of a two-three year period a formal review of the AETC Evaluation Framework occurs, including a particular focus on the outcomes collected by RedCap as the electronic data capture platform.

This timeframe was seen as a good balance between ensuring that:

- 1) Adequate collection of data to complete a meaningful analysis can be achieved,
- 2) Testing a new data collection system with young people and carers can occur with a good sample size on a 'new system',
- 3) Outcomes related to the AETC MOS delivery can be reviewed after a relatively short period of time to ensure that the service is operating as per the MOS.

Following the implementation of the framework and the collection of data, a thorough evaluation needs to occur to provide responses to the identified short-term outcomes guiding the evaluation framework. This would include responding to the questions pertaining to process, impact, and outcomes, and implications for future program and policy for adolescents experiencing severe, persistent, and complex mental health issues.

CONSIDERATION 6.0 –That an external evaluation occur at the conclusion of two to three years to provide recommendations and considerations for the longer term implementation of the evaluation, including benchmarking against other Adolescent Extended Treatment (AET) services. At this point it is recommended that outcomes are analysed.

Consideration 7.0

An Ethics application should be completed once the AETC is operationalised.

In the original endorsed document (*"Evaluation Framework for the Adolescent Extended Treatment Centre (AETC): Preliminary Report for the Mental Health Alcohol and Other Drugs Branch (MHAODB)"*). QCMHR indicated that they would complete an Ethics application to the CHQ HHS Human Research Ethics Committee (HREC) in order to collect and collate the data. However, this

will not be possible. In order for an Ethics committee to appropriately assess the merits of an application they need very specific detail around process and collection. At the time that this document was authored these processes were not completed, and the full information required for an ethics committee was not available. A guide for an ethics application has been completed by QCMHR, but the submission of this needs to occur via CHQ HHS, with MHAODB support.

A guide to support this application, based on the CHQ Ethics process, will be provided by QCMHR.

APPENDIX A

Questions to guide the selection of evaluation tools and development of clinical indicators to meet the short, medium and long-term outcomes.

<p>Process</p>	<ul style="list-style-type: none"> • Has the AET MOS been implemented as intended? • Has the intake panel been effective? • Have program participants (staff, community organisations, community members) been satisfied with the AETC? • Have all the service activities been delivered? • How effective were: <ul style="list-style-type: none"> ○ The team serving the designated population of adolescents with severe and persistent mental illness according to AET MOS? ○ The AETC staff at participating in the evaluation process?
<p>Outputs and Outcomes</p>	<ul style="list-style-type: none"> • Have the AET MOS key objectives been achieved? • Who are the adolescents that attended the AETC? • What is the experience of young people who accessed the AETC? • Has the AETC team functioned effectively? Have people adhered to their RD? • What have been the critical success factors and barriers to achieving the impacts and outcomes? • What outcomes are experienced by young people involved in the AETC in relation to functioning? • How do young people's family members experience the ATEF? • How do the outcomes of the AETC compare with other models of sub-acute services? • What is the impact post-AETC on consumer's acute admissions and ED presentations? • What is the impact of an AETC admission on consumer's school attendance or vocational status? • Is the cost reasonable in relation to the magnitude of the benefits? • Have levels of partnership and collaboration increased?
<p>Implications for future program and policy</p>	<ul style="list-style-type: none"> • Should the program be continued and developed further? • What performance monitoring and continuous quality improvements arrangements should be maintained in the future? • How will the program, or the impacts of the program, be sustained? • What earlier-orientated intervention programs in a consumer's journey through Queensland mental health services could possibly stop the need for a sub-acute admission to the AETC? • How does an AETC admission compare with longer term multiple acute admission?

APPENDIX B

Recommendations

RECOMMENDATION 1: ENSURE HIGH-LEVEL SUPPORT FOR AETC EVALUATION

FRAMEWORK AND IMPLEMENTATION.

- R.1.1 Ensure support and buy-in from high-level decision makers at the MHAODB and CHQ
- R.1.2 Establish formal and informal partnerships with other key data agencies (e.g., Analysis and Accountability team, Clinical systems, collections and Performance Unit) and other services within the sub-acute and non-acute continuum (e.g. Assertive Mobile Youth Outreach Service [AMYOS] and Day programs).
- R.1.3 Provide representation from QCMHR on a CHQ-lead AETC implementation team.

RECOMMENDATION 2: DEVELOP A SIMPLE SET OF CONCRETE MEASURES THAT ARE FEASIBLE TO COLLECT THE DATA FOR DURING IMPLEMENTATION.

- R.2.1 Develop a simple set of measures that are easy to collect in a consistent manner. *The Advisory Group has endorsed a set of data instruments for adolescents, carers or significant others, and clinicians. This recommendation has been completed and is presented in Appendix C.*
- R.2.2 Identify and investigate potential platforms for electronic data collections to ensure efficient data collection from adolescents, carers, and clinicians.
- R.2.3 Identify where it will be important to link data collection to mechanisms that are already underway. The Clinical System, Collections and Performance Unit has well-developed performance monitoring frameworks and indicator reports that the AETC evaluations can utilise.
- R.2.4 Program and system outcome reports (identified by key stakeholders involved in the implementation of the AETC) should be linked to data collection collated by the state-wide Analysis and Accountability team.

RECOMMENDATION 3: EXPLORE OPTIONS FOR SOFTWARE SPECIFIC TO AETC DATA COLLECTION AND OTHER SUB-ACUTE SERVICES.

- R.3.1 Explore the feasibility, cost, and ongoing ethics restrictions associated with the use of an electronic data collection platform (e.g., RedCap).
- R.3.2 Explore feasibility of a 2-3-year pilot study to test an electronic data collection platform. This is to be presented and discussed at the AETC Advisory Group.
- R.3.3 Explore legal, hardware-related, and other issues associated with data management systems within Queensland Health.

RECOMMENDATION 4: IMPLEMENT THE EVALUATION FRAMEWORK.

- R.4.1 Work with the CHQ AET Implementation team and (to be appointed) Clinical Director of the AETC to establish effective, feasible, and streamlined processes and business rules to support the data collection.
- R.4.2 Develop an online training program to orientate clinical staff to the evaluation tools and standardise processes. This will ensure; (i) fidelity of the data collection; (ii) explain the rationale and benefits of collection; and (iii) develop a culture of best practice evaluation.
- R.4.3 Design and create a brief animated educational video for consumers regarding the evaluation framework and tools used within the AETC.
- R.4.4 Pilot the evaluation tools with a sample of consumers prior to the AETC opening to assess the level of feasibility, sensitivity, and accuracy.
- R.4.5 Complete (if required) an application to the CHQ Human Research Ethics Committee (HREC) in order to collect data.

RECOMMENDATION 5: COLLECT AND ANALYSE DATA BASED ON COHORTS OF CLIENTS

WHO ATTENDED THE AETC.

- R.5.1 Collection and analysis of the data over the pilot period will be complex. A balance between ensuring that data collection and 'cleaning' occurs in addition to an ability to report, analyse and ensure quality processes are progressed will be critical to the success over the recommended pilot study period and developing a longer term processes based on outcomes of the pilot evaluation period.
- R.5.2 Following the implementation of the framework and the collection of data, a thorough evaluation needs to occur to provide responses to the identified short-term outcomes guiding the evaluation framework. This would include responding to the questions pertaining to process, impact and outcomes, and implication for future program and policy for adolescents experiencing severe, persistent, and complex mental health issues. A guide of questions to be answered is presented in Table 2.1, p8, Chapter 2.

APPENDIX C

	Adolescent	Family, carers, friends	Clinician, treating team	Operational	AET-MOS	
Category	Symptom Change Co-morbidities Trauma History Culture	Likert scale (how I am feeling) SDQ	Preliminary diagnosis TA status ACE* HoNOSCA	Chart review (KPIs)	4.3.1 4.3.2 4.2.3 4.3.6 4.3.7 4.5.2 4.8.3	
	Substance Use	Drug/alcohol use	Drug/alcohol use HoNOSCA		4.3.11	
	Risk Assessments	Suicide risk indicator	Suicide risk indicator HoNOSCA	CIMHA quarterly report	4.3.8 4.3.9	
	Work Education	PLP GBO satisfaction	Psychosocial info HoNOSCA PLP		4.1.2 4.1.5 4.4.1 4.4.5	
	Social Connectedness Relationships	RAS SDQ GBO satisfaction	Goals Based Outcomes (GBO) (Y/N) HoNOSCA		4.4.1	
	Gender Identity [‡]	Gender Q	Gender Psychosocial info		4.1.4	
	Physical Health GP relationships		Physical health questions HoNOSCA	CIMHA report (KPIs)	4.1.3 4.3.10 4.6.1 4.6.2 4.6.3	
	Functioning [‡]	RAS SDQ GBO satisfaction	Psychosocial info HoNOSCA		4.4.1	
	Family/Carers Family functioning		Relative Stress Scale (RSS) SCORE-15 Parent/carer Contextual Outcomes	Family therapy consideration	4.4.3 4.5.3	
	Service, partnerships, transfer of care	YES [*]		Previous Service History* Post-collection tool [†]	CIMHA business rules Mandatory clinical documentation CIMHA quarterly reports	4.1.1 4.3.13 4.7.1 4.7.2 4.10 4.11 4.12
	Individualised, integrated, client-centred, recovery-based care	PLP	PLP	Education information pack PLP	Recovery plan CIMHA Report	4.2.3 4.4.2
	Referral/cohort				Panel Data Sheet Quarterly Reports	4.2.1 4.2.2 4.2.4
	Informed, supported workforce				Ongoing Annual reports (TBD) CIMHA Quarterly Reports	4.8.1 4.9

* Intake Only

† Discharge Only

APPENDIX D

Clinician Survey

Clinician PRE

NOTE: Please be aware that branching logic and calculated fields will not function on this page. They only work on the survey pages and data entry forms.

Consumer code.

This code will consist of the FIRST 3 letters of the young person's SURNAME, followed by the FIRST 3 letters of their FIRST NAME, followed by their MONTH and FULL year of birth.

E.g. If the young person was named Jenny Andrews and she was born on the 01/01/2004, her CONSUMER CODE would be ANDJEN012004

* must provide value

Date

* must provide value

 D-M-Y

Date of birth

* must provide value

 D-M-Y

Age

AETC Clinician

Suburb (at referral)

Currently under TA

- Yes
 No

TA = Treatment Authority

reset

Primary Diagnosis

Secondary Diagnosis

Current medications

Expand

Current CYMHS client

- Yes
 No

CYMHS = Child and Youth Mental Health Service

reset

If yes, total number of months open service episode with CYMHS prior to referral?

Previous CYMHS client?

- Yes
 No

CYMHS = Child and Youth Mental Health Service

reset

If yes, total number of months open service episode with CYMHS prior to closure?

Number of emergency department psychiatric presentations*?

*in the last 3 months

Number of mental health acute inpatient admissions*?

 *in the last 3 months

Attended AMYOS program?
 Yes
 No
 AMYOS = Assertive Mobile Youth Outreach Service
 reset

Attended YRRU?
 Yes
 No
 YRRU = Youth Residential Rehabilitation Unit
 reset

Attended Day Program?
 Yes
 No
 reset

Height (cm)

Weight (kg)

BMI.
 To calculate BMI divide WEIGHT (in kg) by HEIGHT (in meters squared).
 E.g. If a young person was 169cm tall and weighed 57kg, BMI would be $57/1.69^2 = 57/2.85 = \text{BMI } 20$.

Minimum HDL (mmol/L)

Type 2 diabetes?
 Yes
 No
 reset

Has a GP been identified?
 Yes
 No
 reset

To which gender does the young person most identify with?
 Female
 Male
 Transgender female
 Transgender male
 Gender Variant/Non-conforming
 Prefer not to answer

Culture
 Aboriginal
 Torres Strait Islander
 CALD

Refugee background or asylum seeker?
 Yes
 No
 reset

Education

* must provide value

- Not attending
- Distance Education
- Flexi
- Home School
- Mainstream
- Special Education
- TAFE or vocational training

Current level at school?

e.g. Year 9 would be as "9" only.

In the last 3 months, how often did the young person fail to attend school?

- Never
- Hardly ever
- Sometimes
- Most of the time
- All of the time

reset

As a result of these problems, how many days has the young person been absent from school in the last 3 months?

When the mental health issues/difficulties were at their worst, how much did it impact the young person's ability to participate in or complete their schoolwork?

- Not at all
- A little
- Somewhat
- A lot
- Extremely
- Don't know
- Refuse to answer

reset

Has the young person started any of the following?

- Paid full-time work
- Paid part-time work
- Volunteer work
- Other

If yes to employment, was it stopped prior to admission?

Child safety involvement?

- Current
- Past
- None

reset







Family structure (young person's current living situation)?

- Intact family
- Single parent
- Step or blended family
- Other

reset







Note: "Intact" refers to 2 biological parents caring for the young person in the same residence.

Has the young person ever been placed in statutory out-of-home care?	<input type="radio"/> Yes <input type="radio"/> No					reset
Has the young person spent time incarcerated previously?	<input type="radio"/> Yes <input type="radio"/> No					reset
Risk Assessment (in the last month)						
	Most days	Weekly	Monthly	Less than monthly	None	
Suicidal ideation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Suicidal attempts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Self-harm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Unsafe/risky sex/at risk of exploitation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Violence/aggression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Drug and Alcohol Use (over the past month)						
	Most days	Weekly	Monthly	Less than monthly	None	
Alcohol	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Amphetamine type	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Benzodiazepine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Caffeine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Cannabis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Hallucinogens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Inhalants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Synthetics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Tobacco	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

      Variable: trauma

Does the young person have a trauma history? Yes
 No

* must provide value reset

      Variable: trauma_history [Branching logic exists]

Trauma History (please tick all that apply).

- Physical abuse
- Sexual abuse
- Emotional abuse
- Neglect
- Witness DV/FV
- Sexual assault
- Physical assault
- Serious accident
- Natural disaster
- War
- Death/serious illness of significant other
- Intergenerational history of trauma

Clinician POST

NOTE: Please be aware that branching logic and calculated fields will not function on this page. They only work on the survey pages and data entry forms.

Consumer code.

This code will consist of the FIRST 3 letters of the young person's SURNAME, followed by the FIRST 3 letters of their FIRST NAME, followed by their MONTH and FULL year of birth.

E.g. If the young person was named Jenny Andrews and she was born on the 01/01/2004, her CONSUMER CODE would be ANDJEN012004

* must provide value

Date

 D-M-Y

* must provide value

Date of birth

 D-M-Y

* must provide value

Age

AETC Clinician

Date of closure

 D-M-Y

Duration* of AETC service episode?

*in weeks

Currently under TA

- Yes
- No

reset

TA = Treatment Authority

Reason for transfer of care

- Age limit reached
- Deceased
- Imprisoned
- Planned closure (without treatment goals met)
- Treatment goals met
- Unplanned closure

Care transferred to

- Adult MH
- AMYOS
- CYMHS
- Day Program
- GP
- Headspace
- NGO MH
- No referral required
- Other
- Private allied health
- Private Psychiatry
- Step-Up-Step-Down
- YRRU

I can handle what happens in my life * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I like myself * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have a purpose in life * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
If people really knew me they would like me * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
If I keep trying, I will continue to get better * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have an idea of who I want to become * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Something good will eventually happen * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I am the person most responsible for my own improvement * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I am hopeful about my own future * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I know when to ask for help * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I ask for help when I need it * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I know what helps me get better * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I can learn from my mistakes * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Recovery Assessment Scale - Mastering My Illness					
	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE	
I can identify the early warning signs of becoming unwell * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Other services involved during service episode (evidence of collaboration documented in client record)

- Child safety
- CYFOS
- Day Program
- Education
- GP
- NDIS provider
- NGO
- Other Health
- Other MH
- Youth Justice

Therapy (rehabilitation and recovery)

In the past 4 weeks, has the consumer attended recovery sessions?

	None	1-4	5-10	>10	
Psychoeducation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Skills Training - therapeutic skills training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Art therapy / Music therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Planned educational/vocational activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Health & fitness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Consumer, family, & carer support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Community links	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

	Most days	Weekly	Monthly	Less than monthly	None	
Suicidal ideation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Suicidal attempts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Self-harm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Unsafe/risky sex/at risk of exploitation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Violence/aggression reset

Has there been any drug or alcohol use while in the AETC? Yes No reset

If yes, please provide details

How often was the young person able to complete their recovery (rehabilitation) goals? Never Rarely Sometimes Usually Always reset

Consumer PRE

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* must provide value

Date of Birth

* must provide value

 Today D-M-Y

Gender

- Female
- Male
- Transgender female
- Transgender male
- Gender variant/non-conforming
- Prefer not to answer

reset

Sexual identity

- Heterosexual (straight)
- Same sex attracted/Bisexual
- Unknown

reset

Culture

- Aboriginal
- Torres Strait Islander
- Neither

Recovery Assessment Scale - Doing things I value

	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
It is important to have fun * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
It is important to have healthy habits * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I do things that are meaningful to me * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I continue to have new interests * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I do things that are valuable and helpful to others * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset

I do things that give me a feeling of great pleasure * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Recovery Assessment Scale - Looking forward					
	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE	
I can handle if I get unwell * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I can help my self become better * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have the desire to succeed * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have goals in life that I want to reach * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I believe that I can reach my current personal goals * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I can handle what happens in my life * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I like myself * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have purpose in life * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
If people really knew me they would like me * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
If I keep trying, I will continue to get better * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have an idea of who I want to become * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Something good will eventually happen * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I am the person most responsible for my own improvement * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

I am hopeful about my own future <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I know when to ask for help <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I ask for help when I need it <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I know what helps me get better <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I can learn from my mistakes <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Recovery Assessment Scale - Mastering my illness

	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE	
I can identify the early warning signs of becoming unwell <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have my own plan for how to stay or become well <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
There are things that I can do that help me deal with unwanted symptoms <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I know that there are mental health services that help me <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Although my symptoms may get worse, I know I can handle it <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
My symptoms interfere less and less with my life <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
My symptoms seem to be a problem for shorter periods of time each time they occur <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Recovery Assessment Scale - Connecting and belonging

	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
I have people that I can count on * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
Even when I don't believe in myself, other people do * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
It is important to have a variety of friends * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I have friends who have also experienced mental illness * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I have friends without mental illness * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I have friends that can depend on me * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I feel OK about my family situation * must provide value				

CONSUMER POST

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* must provide value

Date

* must provide value

  Today D-M-Y

Date of birth

* must provide value

  Today D-M-Y

Age

* must provide value

How often were you able to complete your recovery goals?

* must provide value

- Never
- Rarely
- Sometimes
- Usually
- Always

reset

Patient experience

	Never	Rarely	Sometimes	Mostly	Always
I was kept informed as much as I wanted about my treatment and care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
I was involved as much as I wanted in making decisions about my treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
When it comes to your healthcare do you feel we focus on what is important to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset

The best things about this service were:

Expand

My experience would have been better if:

Expand

Recovery Assessment Scale - Doing things I value

	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
It is important to have fun <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
It is important to have healthy habits <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I do things that are meaningful to me <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I continue to have new interests <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I do things that are valuable and helpful to others <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I do things that give me a feeling of great pleasure <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset

Recovery Assessment Scale - Looking Forward

	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
I can handle if I get unwell <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I can help myself become better <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I have the desire to succeed <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I have goals in life that I want to reach <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset
I believe that I can reach my current personal goals <small>* must provide value</small>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
				reset

I can handle what happens in my life * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I like myself * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have a purpose in life * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
If people really knew me they would like me * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
If I keep trying, I will continue to get better * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I have an idea of who I want to become * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Something good will eventually happen * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I am the person most responsible for my own improvement * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I am hopeful about my own future * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I know when to ask for help * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I ask for help when I need it * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I know what helps me get better * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I can learn from my mistakes * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Recovery Assessment Scale - Mastering My Illness					
	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE	
I can identify the early warning signs of becoming unwell * must provide value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

<p>I have my own plan for how to stay or become well * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>There are things that I can do that help me deal with unwanted symptoms * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>I know that there are mental health services that help me * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>Although my symptoms may get worse, I know I can handle it * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>My symptoms interfere less and less with my life * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>My symptoms seem to be a problem for shorter periods of time each time they occur * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Recovery Assessment Scale - Connecting and Belonging

	UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE	
<p>I have people that I can count on * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>Even when I don't believe in myself, other people do * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>It is important to have a variety of friends * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>I have friends who have also experienced mental illness * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>I have friends without mental illness * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
<p>I have friends that can depend on me * must provide value</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

I feel OK about my family situation
* must provide value

reset

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* must provide value

For each line, would you say this describes our family:

	Not at all	Not well	Partly	Well	Very well
In my family we talk to each other about things which matter to us	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
People often don't tell each other the truth in my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
Each of us gets listened to in our family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
It feels risky to disagree in our family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
We find it hard to deal with everyday problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
We trust each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
It feels miserable in our family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
When people in my family get angry they ignore each other on purpose	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
We seem to go from one crisis to another in my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
Things always seem to go wrong for my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
People in my family are nasty to each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset
People in my family interfere too much in each other's lives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
					reset

In my family we blame each other when things go wrong	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
We are good at finding new ways to deal with things that are difficult	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Relative Stress Scale (RSS)						
	Never	Rarely	Sometimes	Often	Nearly always	
Do you ever feel like you can no longer cope with the situation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever feel that you need a break?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever get depressed by the situation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Has your own health suffered at all?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you worry about accidents happening to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever feel that there will be no end to the problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you find it difficult to get away on holiday?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
How much has your social life been affected?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
How much has the household routine been upset?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Is your sleep interrupted by _____?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Has your standard of living been reduced?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever feel embarrassed by _____?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Are you at all prevented from having visitors?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever get cross and angry with _____?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever feel frustrated at times with _____?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

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* must provide value

For each line, would you say this describes our family:

	Describes us NOT AT ALL	Describes us NOT WELL	Describes us PARTLY	Describes us WELL	Describes us VERY WELL	
In my family we talk to each other about things which matter to us	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
People often don't tell each other the truth in my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Each of us gets listened to in our family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
It feels risky to disagree in our family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
We find it hard to dealt with everyday problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
We trust each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
It feels miserable in our family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
When people in my family get angry they ignore each other on purpose	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
We seem to go from one crisis to another in my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
When one of us is upset they get looked after within the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Things always seem to go wrong for my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
People in my family are nasty to each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

People in my family interfere too much in each other's lives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
In my family we blame each other when things go wrong	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
We are good at finding new ways to deal with things that are difficult	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Relative Stress Scale (RSS)						
	Never	Rarely	Sometimes	Often	Nearly always	
Do you ever feel like you can no longer cope with the situation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever feel that you need a break?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever get depressed by the situation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Has your own health suffered at all?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you worry about accidents happening to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever feel that there will be no end to the problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you find it difficult to get away on holiday?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
How much has your social life been affected?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
How much has the household routine been upset?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Is your sleep interrupted by _____?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Has your standard of living been reduced?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Do you ever feel embarrassed by _____?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Are you at all prevented from having visitors?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever get cross and angry with _____?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
Do you ever feel frustrated at times with _____?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	
I feel supported by my child's AETC clinician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel AETC improved my child's emotional stability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel AETC improved my understanding of my child's mental health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel AETC helped me accept my child's mental health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel AETC improved my child's mental health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel AETC assisted to decrease the frequency of my child's mental health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel AETC met my child's expectations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel AETC met my expectations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel AETC assisted to decrease the severity of my child's mental health problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset
I feel more hopeful about my child's future because of AETC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	reset

Appendix E

PLEASE NOTE ALL CHQ HHS HRECS NOW GO THROUGH ERM – THE INFORMATION IN THIS DOCUMENT WILL HELP WILL FILL OUT THE ONLINE ERM APPLICATION

The information provided in this document highlighted in yellow is a guide of what could be included in a HREC for the AETC Evaluation Project.

The rest of the information provided in this document are general CHQ HHS HREC guides.

Children's Health Queensland Research Protocol Template

A well written and complete protocol is essential for a high quality research project. A study protocol generally follows a conventional layout. There are several templates already available although most are developed for commercially-sponsored randomised controlled studies. This research protocol template aims to offer CHQ medical, nursing, midwifery and allied health researchers a more generic guide suitable for a broader range of clinical and scientific research enquiries.

The preparation of a protocol is an important first step in the research process for the following reasons:

It states the research question you aim to answer;

It encourages adequate consideration and planning of project detail *before* you begin;

It allows co-investigators or peers a living and dynamic document for contribution and early review prior to its completion;

It acts as a record and reminder for you and your supervisor (co-investigator or co-worker) of the initial project aims and stated procedures. This record also enables you to monitor the progress of your project; and

It provides the basis for funding or human research ethics applications.

The template contains a broad outline of sections usually expected in a research protocol. It is a guide to the information conventionally required rather than aiming to be definitive. Therefore, not all of the sections will be relevant for every study protocol and may be modified or deleted as applicable.

Evaluation of the Adolescent Extended Treatment Centre: Results from a 2-year pilot trial.

A well-constructed study title is important as it is the first opportunity to attract the attention of the reader. The study title should be descriptive, although clearly and concisely indicating the subject of inquiry. Having a refined research question can assist in constructing a title. This will ensure that your study title reflects (if appropriate) the patient population, intervention (e.g. medicinal product or device), comparator (e.g. another intervention, placebo or usual care) and outcome. You might also consider incorporating the design type (e.g. a randomized controlled study, case-control study, or retrospective cohort study) as is recommended to improve the *reporting* of health research (e.g. Consolidated Standards of Reporting Studies). However, your initial title will only be a working title that would usually be revised as your study becomes more refined. The final title should be consistent across all related documents (including regulatory documents if applicable). You might also like to include a 'lay' ('public' or 'simplified') title easily understood by non-medical or interdisciplinary persons. These are sometimes asked for in funding applications, Human Research Ethics Committee (HREC) submissions, and clinical study registries.

e.g. "A randomized controlled trial to evaluate the effect of tight glycaemic control in the paediatric intensive care unit".

STUDY INVESTIGATOR(S)

Principal Investigator (A): Ms Iama Flamingo¹

Ph. 3068 xxxx

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Principal Investigator (B): xxxxx²

Co-Investigator (A): xxxxx¹

Co-Investigator (B): xxxxx²

1. Institution, street, suburb, city, state, country, etc.

2. Institution, street, suburb, city, state, country, etc.

1. INTRODUCTION

The introduction is a very brief overview of study (~250 words). The introduction should be concise but sufficient to orientate the reader to the main purpose of the study, how it will be conducted and its expected benefits. It is a structured sketch of the study that will provide an overview before examining the details. It is placed at the head of the protocol but is often written after the protocol itself is completed.

2. BACKGROUND

[You would also need to cite literature about the topic in this section]

The evaluation of mental health services for children and adolescents is a widely talked-about, but grossly under-reported, area of research. There are lots of examples of the types of services that serve children and adolescents with mental health issues, especially more recently those with more severe and complex illness. [You could expand here about the AET services that have come on board in recent years]. While many of these services have been established over the last 5-10 years, there remains a lack of evidence around their efficacy, cost, and the short- and long-term outcomes of the young people that utilise such services.

Service evaluation, by definition, is the XXXXX. It is often underpinned by program logic models and evaluation frameworks which guide service delivery based on inputs, activities, outputs and outcomes. Such a model was used in the development of the Adolescent Extended Treatment Centre Evaluation (AETC) Framework. Program logic principles and extensive stakeholder engagement, and guidance from the Adolescent Extended Treatment Model of Service (AET MOS) were used to develop an evaluation framework for this new service.

[Introduce what the AETC is]

The AETC provided a unique experience in youth mental health service evaluation in Queensland. Unlike many other mental health services, which develop an evaluation framework/report on evaluation after the service has been running for some time, the AETC had this opportunity before the service was operational. This allowed stakeholder engagement and thorough research, at the outset, as to what would and would not be included and/or feasible in a service evaluation. Therefore, the data gathered from the evaluation pilot trial is the first of its kind for an adolescent health service for those with severe and complex mental illness.

The goals of the evaluation framework project were three-fold (reflecting the short, medium, and long-term objectives, respectively); (i) understand the cohort of young people that enter the AETC, (ii) to identify consumer outcomes achieved by the AETC (and how these might compare to similar services across the state), (iii) to better understand consumer journeys across the health sector (both pre, during, and post-AETC). The purpose of this study is to focus on objectives (i) and (ii) with the evaluation data gathered from the two year pilot trial.

It is hoped that the results from this evaluation will guide ongoing program development and quality improvements to successfully meet the goals of the service and of the AET MOS. This project will also provide an evidence-base for the evaluation of a mental health service for adolescents with severe and complex mental health needs.

The most important aspect of a research proposal is the clarity of the research problem.

This is an opportunity to convince the reader (or reviewer) of why the study needs to be done (and deserves funding or ethical approval). Keep this brief and to the point (approximately two A4 pages). The following key points may be used as a guide:

Conduct a comprehensive literature search (Cochrane, Medline, Embase and other databases relevant to your area of study).

Discuss the importance of the topic (public health and/or clinical importance and impact on individuals/community; incidence, prevalence, mortality and morbidity).

Critically appraise the relevant literature and discuss the state of current knowledge on the topic (including deficiencies in knowledge or gaps that make the study worth doing).

Indicate how the research question has emerged and fits logically with the above.

Outline your approach to address the research question.

Explain how your study will contribute to existing research and benefit other individuals or the wider community.

Discussion should be clear and logical that demonstrates you are fully conversant with the ideas presented and can grasp their methodological implications. Aim to be concise and present only key sources rather than an exhaustive list of cited references (limit to approximately 20-25 key papers). The literature review should logically lead to the statement of the aims of the proposed project.

3. AIM(S) OF STUDY

The aim of this study is to understand what kinds of young people attend the AETC (age, location, diagnosis, complications etc.) and what factors affect their recovery and rehabilitation in the AETC.

Your aim(s) should arise from your literature review and state what the study hopes to accomplish.

4. OBJECTIVES

To understand the cohort of young people that come to the AETC.

To identify and quantify consumer outcomes achieved by the AETC.

Your focused research question needs to be further refined into one or more study *objectives*. The study objective(s) should be single and quantifiable statement(s) that will allow you to answer your research question.

e.g. The objective of this study is to determine if socioeconomic status is associated with excess childhood asthma in Paris.

5. HYPOTHESIS

5b. Primary Hypothesis

Hypotheses are more specific than objectives and amenable to statistical evaluation. Your primary hypothesis is your statement of the hypothesised effect on the primary outcome measure. A hypothesis is worded very simply and written as 'testable' statements. Your experimental results will prove or disprove your hypothesis. Hypotheses are generally stated in the null form (H_0) as they have their basis in inferential statistics. Rejecting the null hypothesis increases our confidence, with a given level of probability, that there is a relationship between the variables being studied. However, a classic scientific hypothesis includes both a null and alternative (H_a) hypothesis.

e.g. H_0 : Asthma prevalence rates are not different among children from low and high socioeconomic groups in Paris.

H_a : Asthma prevalence rates are different among children from low and high socioeconomic groups in Paris.

5b. Secondary Hypotheses

Although a study is usually based around a primary hypothesis, secondary hypotheses may also be pre-specified although based on outcomes of lesser importance or additional interest. As the primary hypothesis is usually the basis for statistical power calculations, secondary hypotheses with insufficient power will generally not lead to statistically robust conclusions.

6. STUDY DESIGN

This study will be a before-and-after design, utilising data from those adolescents in the AETC (and their carers) upon entry to, and exit from, the AETC.

State the design of the research (e.g. randomised controlled study, cross-sectional survey, prospective or retrospective cohort/case-control). Whatever the study design, you need to ensure that you provide the reader with a clear statement and description of your proposed design. You may also explain why the particular study design has been chosen in preference to other possible designs (i.e. justification for choice of study design).

7. STUDY SETTING/LOCATION

This will be a single-site study conducted at the AETC, located in Northern Brisbane.

The location of where the study will be conducted (e.g. Respiratory Department, Lady Cilento Children's Hospital). You need to mention whether the study is going to be a single-centre study or a multi-centered study (i.e. conducted in more than one location).

8. STUDY POPULATION

The study will comprise of all those young people in the AETC that give consent for their evaluation and outcome data to be used in this study. Carers of the young people in the AETC who complete Carer surveys and agree for their data to be used will also be included in the study population to investigate secondary outcomes. It will also be important to include data from those adolescents who are referred to, but not accepted into, the AETC for evaluation purposes. Discussion about the state-wide focus on the consumers is essential and that the data collected may need to be linked with other HHS services.

Defining the group in which the study will be carried out on provides the setting for which the research has relevance. This section also describes how one can be certain that the results from your sample population can be generalised to the target population of interest. This section should describe the target population, including:

Population the subjects will be drawn from

All aspects of subject selection

The total number and number within any subgroups

9. ELIGIBILITY CRITERIA

Inclusion and exclusion criteria are standards that you have set determining whether a person may or may not be allowed to enter your study. They are used to identify appropriate participants and to ensure their safety.

9a. Inclusion criteria

Young people in the ATEC, who will be between 12 and 21 years of age, and have a mental health diagnosis that is considered to be severe, persistent, and complex. Inclusion criteria also include adolescents who were referred to the AETC service, but who are not accepted into the AETC after the panel selection process.

Inclusion criteria are the 'characteristics' that clearly describe the study population that are required for a subject to be included in the study. The criteria may be based on factors such as age, gender, the type and stage of a disease, previous treatment history, and co-morbid medical conditions. They may state appropriate criteria for admitting special 'at-risk' populations such as women of reproductive age, children or patients with disease states or organ impairment.

9b. Exclusion criteria

Provide details of participants that will be considered ineligible to participate and justification for their exclusion. These criteria are not always clinical in nature, aiming principally to accommodate participants in a safe and ethical manner. Criteria may include circumstances that interfere with the participant's ability to give informed consent (diminished understanding or comprehension, or a language other than English spoken and an interpreter unavailable), contraindications to the study treatment(s)/procedure(s), taking certain concomitant medication(s), or conditions that interfere with a patient's ability to comply with all treatment(s)/procedure(s).

10. STUDY OUTCOMES

10a. Primary Outcome

The primary outcome is to establish who the cohort of young people are that enter the AETC and the effectiveness of the AETC MOS. This will include demographic data, diagnoses and comorbidities and other relevant factors that distinguish the population at the AETC as well as changes in psychological, social and family functioning during the AETC.

The primary outcome should be the most important and clinically relevant outcome (e.g. clinical, psychological, economic, or other) of the study. This is the measure used to answer your study aim. However, it is also the outcome used to calculate study sample size and power and test the primary research hypothesis. Generally, no more than 1-2 primary outcome measures are pre-specified. Primary outcome measures may be measured in various ways such as: binary (two possible outcomes to a certain situation); continuous (measurement on a numerical scale); ordinal (variables have natural, ordered categories and the distances between the categories is not known); time to event, and counts.

10b. Secondary Outcome(s)

Secondary outcomes could include characteristics of young people who are not accepted to the AETC, and how these may/may not differ from those who are accepted and stay at the AETC.

Secondary outcome(s) are measures of additional or less important research interest. They may include additional clinical, psychological, economic, or safety outcomes (e.g. treatment related side effects/adverse events). However, as these endpoints are not used to calculate study power and sample size it is often not possible to draw robust conclusions from the results.

11. STUDY PROCEDURES

This section should describe exactly what is going to happen during conduct of the study. It is preferable to use the active voice and state in the future tense (e.g. "We will randomly allocate participants to...").

11a. Recruitment of participants

This section should describe which potential participants will be identified/selected for recruitment (e.g. via outpatient clinic, medical records search), how they will be approached/asked to participate and how consent will be obtained. You may need to justify the feasibility of recruiting the required number of subjects and estimate the proportion that you would expect will agree to participate. Finally, the period of time expected to recruit the required number of participants should be stated here.

11b. Randomisation

Include the method (including any software) used to generate the random allocation sequence. Describe type of randomisation performed, ratio of assignment to groups, block size permutation and stratification if applicable. Explain the methods used to conceal group allocation until assignment. Also, include information on who will generate the allocation sequence and who will assign participants into their groups.

This section should also discuss if participants, the investigator, and those assessing/analyzing the outcome(s) will be blind (or masked) to group assignment or if the study will be an open-label study (investigators and subjects know their assigned group).

11c. Study procedure

In this section you need to clearly and comprehensively describe exactly what will happen to participants once they are enrolled in your study. Depending on the study it might include how potential participants will be approached, when they will be randomised, the frequency and duration of visits or whether they are expected to self-complete a daily diary at home, the duration of the study or follow-up, and any measurements taken at each visit (e.g. questionnaires, physical measurements, biological samples).

You should include precise details of the treatment(s)/intervention(s) intended for each group/participant. You should also provide details of any follow-up schedule (i.e. time between visits) and consider how you will monitor participants' adherence with the treatment schedule. You might also describe under which circumstances participants may be withdrawn and how this will occur. A schematic diagram or flow chart may be useful for this section.

For drugs and devices that are commercially available, the protocol must state their proprietary names, manufacturer, chemical composition, dose, duration and frequency of administration.

For drugs and devices that are still in the experimental stage (or commercially available and used for a different indication or mode of administration), an Investigators Brochure (IB) is a required accompanying document to the protocol. The IB is a compilation of clinical and non-clinical data, available pre-clinical experiments in animals and/or results of Phase I/II clinical studies available on the experimental products intended for use in the study in question. It provides study organisers and staff with an understanding of the rationale of the study in order to inform their compliance with the protocol requirements. In these cases the approval of the Therapeutic Goods Administration (TGA) will be required prior to commencing the study. Refer to the TGA website, for further information on submission requirements – www.tga.gov.au).

11d. Measurement tools used

CIMHA data

RedCap data, including;

Recovery assessment scale – Domains and Stages (RAS-DS)

Experience of service questions

Relative Stress Scale (carers)

Carer Contextual Outcomes survey

SCORE-15

Therapy attendance

School attendance

School outcomes [from Education]?

It is essential to state how the data will be collected to assess the primary and secondary outcome(s) of the study (e.g. patient questionnaire, medical charts, routinely collected hospital/research database, biological specimens). Describe at what point(s) of the study data collection will occur. You should make statements that justify the validity of the study measure/instrument. If not, you will have to verify how you will ensure the validity and quality of data being collected. Also, mention here if you are going to have one or more assessors to collect data, their level of training/experience (or how they will be trained), and if you are planning to assess inter-rater reliability (if applicable).

11e. Safety considerations/Patient safety

The safety of research participants is foremost. You will need to provide adequate information on how the safety of research participants will be ensured. This can include procedures for recording and reporting adverse events (and serious adverse events) and their follow-up (mandatory requirement for studies involving intervention or treatments). Remember that even administering a research questionnaire may have adverse psychological effects on susceptible individuals.

11f. Data monitoring (this section can flow on from the one above providing more details on data monitoring and other quality control measures)

This section includes information on the personnel and processes of the Data and Safety Monitoring Committee, the use of study monitors to audit study conduct, any stopping and discontinuation rules pre-specified, and handling of adverse events/serious adverse events.

12. STATISTICAL CONSIDERATIONS AND DATA ANALYSIS

12a. Sample size and statistical power

A sample size or power calculation should be performed. This calculation is used to estimate the number of subjects required to answer your primary study hypothesis with an accepted power. Conversely, it also allows you to estimate what power can be achieved with a limited number of participants. This number is calculated by specifying the magnitude of the effects that are expected (i.e. informed and clinically significant), variability of the measurements and the acceptable degree of type I and II errors. You need to specify the assumptions made for the calculation. It is recommended that you consult with a statistician for this section. Also keep in mind the estimated recruitment rate and whether you need to adjust for anticipated non-responders and losses to follow up.

12b. Statistical methods

The statistical methods used for the study objectives/hypotheses (e.g. t-test, chi-squared, multivariate modeling) must be sufficiently detailed. If conducting a randomized controlled study, you should state whether methods will include an "intention to treat" (ITT) analysis, per protocol analysis, or both. An ITT analysis is preferred as it compares all subjects in the groups to which they were originally randomly assigned (despite withdrawal, treatment failure or cross-over). Consultation with a statistician is strongly recommended.

13. ETHICAL CONSIDERATIONS

You must state that the study will be conducted in full conformance with principles of the “Declaration of Helsinki”, Good Clinical Practice (GCP) and within the laws and regulations of the country in which the research is conducted. You will need to consider and articulate how the quality of the technical aspects have been assured, the potential risks and proposed benefits of the study procedures, the priority of the participants’ interests over those of science or of society and how those interests will be safeguarded, responsibility for liability of injury during the study, how the participants are informed of the study, and how they (or Parent/Guardian) give voluntary consent to participate.

Information on how informed consent is to be obtained should be included.

You will also need to adequately detail methods of data extraction (non-identifiable, de-identified or re-identifiable), and data management, storage and security storage (of paper hardcopies and/or electronic files).

For further information see the National Statement on Ethical Conduct in Human Research (NHMRC, 2007) and see the Children’s Health Queensland Research Ethics Coordinator for advice and guidance on your particular study.

14. OUTCOMES AND SIGNIFICANCE

It may be of value to reiterate the potential benefits of answering the research question and conducting the project. This section restates the justification for the study in terms of the anticipated results. It may be important to specify the implications of the potential results and how the results of this study may inform future research or policy makers.

15. REFERENCES

[World Medical Association Declaration of Helsinki \(1964\)](#)

[Note for guidance on good clinical practice \(CPMP/ICH/135/95 - Annotated with TGA comments\)](#)

[National Statement on Ethical Conduct in Human Research \(2007\)](#)