

# BMJ Open Identifying process and outcome indicators of successful transitions from child to adult mental health services: protocol for a scoping review

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## ABSTRACT

**Introduction:** A significant proportion of youth need to transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS); however, the transition process is not well understood and often experienced poorly by youth. In the effort to design and evaluate standards of practice for transitions, there is a need to identify key elements of a successful transition. The objectives of this scoping review are to: (1) identify definitions of successful transitions from CAMHS to AMHS; and (2) identify indicators that have been used to measure CAMHS–AMHS transition care processes and quality, and outcomes.

**Methods:** We will search 8 electronic bibliographic databases from 1980 to 2016 (eg, Medline, EMBASE, PsycINFO), professional associations, policy documents, and other grey literature to identify relevant material. We will include experimental, quasi-experimental, observational studies, and non-research studies (guidelines, narrative reviews, policy documents) examining the transition from CAMHS to AMHS. 2 raters will independently screen each retrieved title and abstract for eligibility using the study inclusion criteria (level 1), and then will independently assess full-text articles to determine if these meet the inclusion criteria (level 2). Data extraction will be completed and results will be synthesised both quantitatively and qualitatively.

**Ethics and dissemination:** The results of the scoping review will be used to develop a set of indicators that will be prioritised and evaluated in a Delphi consensus study. This will serve as a foundation for the development of the first instrument to assess the quality and success of CAMHS–AMHS transitions. Ethics approval is not required for this scoping study.

## BACKGROUND

Mental health problems are experienced by up to 15% of children and youth at any given time and are associated with considerable morbidity, mortality, healthcare and

## Strengths and limitations of this study

- This will be the first scoping review conducted that provides a comprehensive overview of indicators to assess transition success for child to adult mental health service transitions.
- While details of the literature retrieved will be summarised, the quality of articles and documents will not be assessed given the scoping design.
- This scoping review will be limited to English language publications.

personal costs.<sup>1</sup> Research has shown that as many as 70% of all psychiatric disorders diagnosed before the age of 18 years persist into adulthood.<sup>2</sup> As a result, a significant proportion of youth need to transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS). Yet the transition from CAMHS to AMHS is often fragmented, and the factors associated with successful transition are poorly understood.<sup>3–4</sup> In fact, within the mental healthcare system, the greatest financial and institutional weaknesses, particularly the different funding models and care philosophies, are thought to occur between the transition from CAMHS to AMHS.<sup>3–6</sup> A healthcare transition differs in fundamental ways from a healthcare transfer. While transition is a planned process that addresses a range of therapeutic and developmental needs of the youth with the primary goal to ensure continuity of care,<sup>7</sup> transfer consists of the termination of care in CAMHS and its re-establishment in AMHS.<sup>8</sup> Unfortunately, the transition process is often experienced negatively by youth and their caregivers,<sup>9</sup> and continuity of care appears to be a serious problem among the youth. For example, up to 60% of youth receiving CAMHS drop out of care or fail to make the transition from

CAMHS to AMHS.<sup>5 10 11</sup> Despite acknowledgment by clinicians, researchers and policymakers about the importance of the transition process, few studies have addressed the nature of this transition adequately.<sup>3 4</sup> A recent systematic review<sup>12</sup> of programmes and interventions to support CAMHS–AMHS transitions reported there is little data on transition programme effectiveness. Major methodological barriers may be preventing this research, including the lack of consensus about what constitutes a ‘successful transition’ outcome and the lack of validated instruments to assess the transition processes and their quality. Indeed, a review of the literature revealed there are currently no reliable and valid tools to assess the quality of CAMHS–AMHS transition care processes. Therefore, in order to synthesise the available literature relevant to the measurement of mental health service transition processes and outcomes, a scoping review will be conducted. The objectives are to:

1. Identify definitions of successful transitions from CAMHS to AMHS;
2. Identify indicators that have been used to measure CAMHS–AMHS transition care processes and quality, and outcomes.

The scoping review findings will be used in a Delphi consensus exercise designed to establish a set of indicators for evaluating transitions from CAMHS to AMHS, and transition success.

## METHODS/DESIGN

A protocol for our scoping review was developed according to the methodology developed by Arksey and O’Malley,<sup>13</sup> and further refined by Levac *et al*<sup>14</sup> and by the Joanna Briggs Institute.<sup>15</sup> Specifically, the five-stage approach outlined by Arksey and O’Malley’s scoping review framework and reporting will be used, and the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) flow diagram for scoping reviews<sup>15</sup> explained in detail below.

### Stage 1: identifying the research questions

The team drafted three research questions for the scoping review:

1. How has ‘successful transition’ from CAMHS to AMHS been defined and operationalised?
2. What healthcare process and quality indicators have been used to document CAMHS–AMHS transitions?
3. What adolescent outcomes have been measured throughout the transition process?

### Stage 2: identifying relevant studies

#### Eligibility criteria

We will include all research studies (experimental, quasi-experimental, observational, qualitative) and non-research studies (guidelines, narrative reviews, policy documents) examining the transition from CAMHS to AMHS. We will include studies from all settings,

including acute care, primary care, community services and include local, provincial and national settings. Eligible studies and documents must include a definition of transition, and include indicators or recommendations related to assessing the quality of the transition from CAMHS to AMHS.

### Search strategy

We will search the following databases from 1980 onwards: Medline, EMBASE, PsycINFO, Cochrane Database of Systematic Reviews (all OVID interface), CINAHL (EBSCO), Applied Social Science Index and Abstracts (ProQuest), Sociological Abstracts (ProQuest), and the Campbell Library. The searches will include international articles, but will be limited to English. Bibliographies of the retrieved articles will be searched for additional relevant articles. The search strategy will be developed by an experienced research librarian and will include subject heading and text word terms appropriate to each database. It will use combinations and synonyms of the following terms: mental health, transition, adolescents, indicators, outcomes. The detailed search strategies for Medline is available in an online supplementary appendix A. The Medline search will be translated to other databases, and detailed search strategies from each database will be available from the authors on completion of the scoping review. In addition, an extensive grey (unpublished) literature search will be conducted using Google Advanced and the methods outlined in the Canadian Agency for Drugs and Technologies in Health search tool, ‘Grey Matters’.<sup>16</sup> Experts in the field will be contacted to identify additional relevant studies. Bibliographic details will be downloaded into EndNote.

### Stage 3: study selection

Prior to starting the study selection process, the eligibility criteria will be pilot tested on a random sample of 50 titles and abstracts. The pilot test will continue until agreement between the two investigators reaches  $\kappa \geq 0.75$ .<sup>17</sup> Study selection will proceed in two steps. First, two raters will independently screen each retrieved title and abstract for eligibility using the study inclusion criteria (level 1). Then the full text of potentially eligible articles will be retrieved, and two raters will independently review the full-text articles to determine if these meet the inclusion criteria (level 2). Disagreement between the two reviewers will be resolved in consultation with the principal investigator. Study selection will be completed by the reviewers using Covidence,<sup>18</sup> a web-based software program recommended by Cochrane that streamlines the screening, study selection, and data extraction for literature and systematic reviews.

Results of our search and eligibility screening process will be reported using the PRISMA flow diagram for scoping reviews.<sup>15</sup> It will detail the review decision process, results of the search, study selection, full

**Table 1** Data extraction for the three research questions

	Data to be abstracted
Summary	1.1 Author(s) 1.2 Title 1.3 Citation 1.4 Publication type 1.5 Country of origin 1.6 Research question the study addresses (1, 2 and/or 3) 1.7 Aims/objectives 1.8 Participants (age, sex, inclusion/exclusion criteria)
Research question 1: transition definition	2.1 Definition of transition 2.2 Definition of transition success
Research question 2: process and quality indicators	3.1 Name and description of indicator 3.2 Description of calculation of indicator (numerator, denominator) 3.3 Evidence to support use of indicator 3.4 Results
Research question 3: transition outcomes	4.1 Outcome of interest (construct measured; measurement properties) 4.2 Outcome level (person, family, system)

retrieval, addition of searching reference lists, and a final summary of included articles.<sup>15</sup>

#### Stage 4: data items and data collection process

A data extraction tool has been drafted to capture the following information (table 1):

1. Included study descriptive information: authors, title of publication, year of publication, country of source, language, aims of the study, research design, intervention (if any), comparator (where applicable).
2. Transition definitions and operationalisation: including, age at transition (eg, the age of youth transition between child and adult programmes), transitions policies and/or procedures, programme models of care, and criteria for referral and/or admission to child and adult programmes.
3. Healthcare processes and quality indicators: we will record any measurement properties (eg, tools, instruments details), process (eg, referral timing), outcome (eg, youth attending adult mental health clinic) indicators and how they were measured, and key findings and recommendations as they relate to the research question. Additional characteristics will be added to the charting table through completion of the literature search. Consistent with scoping review methods, the study quality will not be assessed.<sup>13 14</sup>
4. Healthcare transition outcomes: we will record person (ie, youth), family, and system outcomes used

to assess CAMHS–AMHS transitions, and describe how the outcomes are measured (ie, attending medical appointments, adherence to medication or other treatments, understanding characteristics of mental illness, improved emotional and behavioural health, educational and/or vocational engagement).

*Rater training:* Two reviewers will be trained on the data extraction tool by a researcher experienced in extracting data for scoping reviews. The reviewers will review a sample of references and compare extraction results with the aim of reaching excellent agreement ( $k \geq 0.75$ ). If reliable agreement is not reached, the extraction tool will be consecutively refined. Disagreement between the two reviewers will be discussed and a third reviewer will be consulted, if needed.

#### Stage 5: synthesising and reporting the results

Data will be summarised both quantitatively (eg, frequency analysis) and qualitatively (eg, narrative content analysis). The key characteristics of the articles collected in the data extraction tool will be summarised with simple numerical counts and presented in a table. We will create a map of indicators and outcomes measured by number of articles. Qualitative information will be entered into N-Vivo software (NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 10, 2012), and basic thematic analysis will be conducted.<sup>19</sup> Key concepts across the articles will be identified and summarised. The synthesis procedures may be further refined towards the end of the review once the reviewers have had the opportunity to examine the selected articles.

#### DISCUSSION AND DISSEMINATION

The results will be used to develop a set of indicators for assessing: (1) the quality of CAMHS–AMHS transitions, and (2) transition success. These indicators will inform a Delphi consensus study where indicators will be prioritised and evaluated based on the following criteria: importance, scientific soundness, usefulness and feasibility by a team of international experts (ie, clinicians, service providers, youth, parents/caregivers, researchers). The consensus products will enable the development of the first instrument or tool to measure the transition process and success of mental healthcare from youth to adulthood. Given that most youth who require transitions from CAMHS to AMHS do not successfully make the transition and ‘fall through the cracks’ of our healthcare system,<sup>5 10 20</sup> there is a great need for design and delivery of effective interventions and measures to capture the impact. The findings of this scoping review provide the foundation for developing a set of indicators that can be used to measure the effectiveness of CAMHS–AMHS transition interventions. The outcomes will be of utility to researchers, clinicians, policy-makers and most importantly, transitional-aged youth and their families.



Our end-of-project knowledge translation activities include submission for presentation at the American Academy of Child and Adolescent Psychiatry annual conferences in 2017, and the 4th International Youth Mental Health Conference in 2017. This will provide the opportunity to share our findings and obtain feedback from key experts across disciplines in the field. These are ideal venues for disseminating our results to stakeholders who may be designing and evaluating transition interventions. We will also publish the results of the scoping review in an open-source journal to ensure a broad group of stakeholders, particularly those without access to academic licences, can access the scoping review results. Importantly, we will hold consultation meetings with our key stakeholders, service providers, service users, and policymakers to create effective and user-friendly methods to summarise and disseminate the findings. This may include a webinar to present our findings on EENet (Evidence Exchange Network for Mental Health and Addictions),<sup>21</sup> a web-based tool for sharing evidence to a broad range of stakeholders, presentation in research rounds, and presentations to community partner agencies.

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**Competing interests** None.

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**Data sharing statement** The search strategies are available on request to the corresponding author.

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