




BMJ Open Quality indicators for transition from paediatric to adult care for adolescents with chronic physical and mental illness: protocol for a systematic review

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ABSTRACT

Introduction Transition from paediatric to adult care is a complex process, which poses significant challenges for adolescents with chronic physical and mental illnesses. For many, transfer to adult care is associated with poor health and psychosocial outcomes. Quality indicators to evaluate transition to adult care are needed to benchmark and compare performance across conditions and health systems. This systematic review aims to identify quality indicators for successful transition to adult care which can be applied across chronic physical and/or mental illnesses.

Methods Published literature will be searched using MEDLINE, Embase and CINAHL from earliest available date to July 2021. Grey literature will be searched using the Grey Matters tool. Using a set of inclusion/exclusion criteria, two independent reviewers will screen titles and abstracts, followed by full-text review. Disagreements will be resolved by a third reviewer. Study selection and data extraction will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols. Study appraisal will be completed using the Appraisal of Guidelines for Research and Evaluation for Quality Indicators instrument. Extracted quality indicators will be categorised into a conceptual framework.

Ethics and dissemination Results from this review will offer novel insights into quality indicators that may be used to measure and evaluate transition success across conditions, which will be disseminated via a Canadian transition collaborative, workshops and peer-reviewed publication. Extracted quality indicators will be further prioritised in a Delphi study with patients, caregivers and providers. This is a critical step in developing a core set of metrics to evaluate transitions to adult care. Ethics approval is not required as this review will identify and synthesise findings from published literature.

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BACKGROUND

Many adolescents with chronic physical and/or mental illnesses experience significant challenges during their transition from paediatric to adult care.^{1–7} They lose connection with the teams they trust, are required to make more decisions autonomously, receive less psychosocial support and often

Strengths and limitations of this study

- Quality indicators will only be included if developed through consensus-building methodology, and excluded if developed for evaluative studies and/or transition interventions.
- Quality indicators relating to all chronic illness populations, including physical, mental and developmental conditions, will be included.
- Critical appraisal of methods used for quality indicator development will be assessed via Appraisal of Guidelines for Research and Evaluation II instrument.
- A comprehensive grey literature search will be conducted to address publication bias.
- The search will be limited to literature in English language.

lack coordinated care between their multi-disciplinary healthcare teams.^{1 8 9} Although there is variability across health jurisdictions, patients in Canada typically transfer to adult care between 16 and 19 years old.^{10 11} This time of transfer often coincides with other critical milestones occurring in adolescence, making this a challenging period for many.¹² Further, many youth feel they receive suboptimal care, are underprepared and dismissed during the process of transitioning to adult care.^{13–15} Potential patient safety risks associated with this transition include worsening disease states and complications, reduced adherence with treatment, emotional stress and delay or lost to follow-up with their adult provider.^{14 16–21}

Despite the known gaps in transition care, there is no universally accepted definition of successful transition, or consensus on which metrics can be used to evaluate transition success overall.^{17 22–24} Quality indicators are used to assess healthcare delivery, processes and outcomes to monitor and improve quality of care.^{25–27} They are developed using robust



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methodological approaches which incorporate high level evidence and input from experts.^{28 29} Quality indicators are crucial for benchmarking patient, caregiver, provider and system-level performance to allow for meaningful evaluation and comparisons between hospitals, jurisdictions and health systems.³⁰ Currently, there are no universally agreed on quality indicators in transition care which can be used for benchmarking across all chronic illnesses. Consequently, the lack of established universal metrics needed to improve quality of transition services limits advancement in the field.

Previous research has identified several indicators and outcomes of successful transition, such as continuity of care between paediatric and adult services, self-efficacy skills, disease-specific knowledge, treatment adherence and patient satisfaction with the transition process.^{10 31–33} However, many of these quality indicators have been limited to specific disease populations or specialties, hindering its generalisability and universal applicability across jurisdictions in Canada and beyond.

OBJECTIVES AND RATIONALE

The primary aims of this systematic review are to: (1) identify quality indicators of successful transition to adult care in adolescents with chronic illness, including physical, mental and developmental conditions and (2) categorise indicators into a conceptual framework. Given the limited literature integrating the diverse perspectives of all stakeholders, this review will include indicators proposed by patients, caregivers, clinicians and health system leaders. Quality indicators identified by this review will be prioritised in a Delphi study to develop consensus on metrics used to evaluate transition success.

METHODS/DESIGN

Research question

The primary research question was developed based on existing gaps in the literature:

1. What illness-specific and non-illness specific quality indicators have been developed via consensus-building methodology that define a successful transition to adult care based on patient, caregiver, provider or health system-level perspectives?

To answer this question, a systematic review was chosen to evaluate existing quality indicators for transition to adult care. Study will run from January 2021 to October 2021.

Search strategy

The literature search will be conducted using MEDLINE, Embase and CINAHL from earliest available date to July 2021. The search strategy will be developed with insights from a librarian and the research team. It will include a combination of two main concepts: (1) 'transition to adult care' and (2) 'benchmarking'. A detailed search strategy for MEDLINE is provided in online supplemental

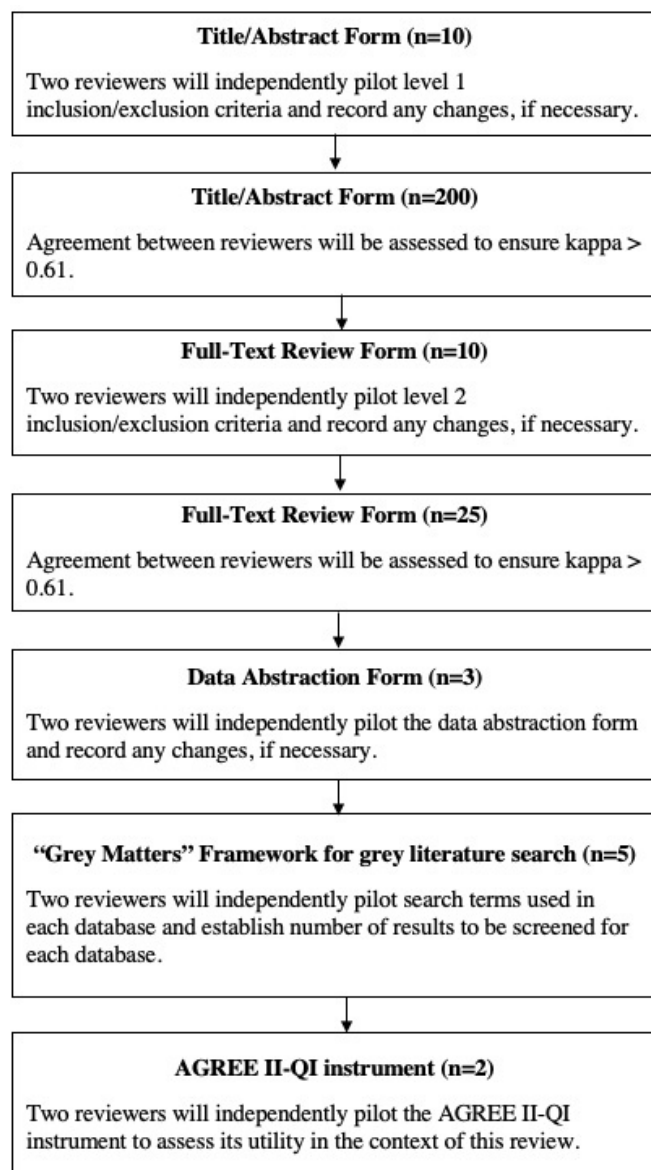


Figure 1 Summary of piloting protocol for systematic review. AGREE II-QI, Appraisal of Guidelines for Research and Evaluation II instrument for Quality Indicators.

appendix A. Titles and abstracts of articles obtained from the search will be exported to an Excel sheet for study selection.

Study eligibility and selection

A title/abstract study eligibility form will be developed by the research team, with involvement of a methodologist with expertise in conducting systematic reviews. Prior to screening articles, the form will be piloted by two independent reviewers (SL and TdLR) with 10 articles to ensure the inclusion/exclusion criteria are appropriate (piloting protocol for entire review is displayed in [figure 1](#)). Changes or clarifications to the study eligibility form will be made and reported in the final manuscript, if necessary. Following this, 200 papers will be screened to assess agreement between reviewers. Adjustments will be

made until kappa >0.61 is achieved, indicating substantial agreement between reviewers.³⁴

Study eligibility will be determined through two distinct steps: title/abstract screening (level 1) and full-text review (level 2). In level 1, studies will be included if they (1) focus on transition from paediatric to adult healthcare services and (2) use metrics or indicators to evaluate transition processes and outcomes. Studies will be excluded if they are not in English or are non-peer reviewed. Assessment of inclusion/exclusion criteria will be completed by two independent reviewers (SL and KB/TdLR). Decisions will be recorded using a study eligibility form administered via GoogleForms. Any disagreements will prompt re-evaluation by both reviewers, followed by resolution by a third reviewer (AT) if consensus cannot be achieved.

Studies included from level 1 will be read in full text and additional inclusion/exclusion criteria will be applied. Specifically, to improve content validity, studies will be included if quality indicators were developed using a robust consensus-building process (eg, Delphi method, prioritisation exercise, RAND/UCLA appropriateness methodology). Studies will be excluded if methodology used to develop quality indicators was not available, or if quality indicators were used to evaluate specific local transition interventions. Full-text review will be conducted by two independent reviewers (SL and KB) and disagreements will be resolved by a third reviewer (AT). Inter-coder agreement for both title/abstract and full-text screening will be measured using Cohen's kappa.

Data extraction

Data from included literature will be extracted using an abstraction tool developed on Microsoft Excel. The tool will include the following components: (1) study information (eg, title; author; year of publication; country;

context/setting), (2) study methodology (eg, study design, population, illness/condition) and (3) quality indicator information (eg, quality indicator description; category of indicator; perspective of indicator). A detailed data abstraction form is included in [table 1](#). The data abstraction tool will be piloted for the first three studies and changes will be made accordingly. Data will be extracted by two independent reviewers (SL and KB) using two separate data abstraction forms. The information extracted will then be combined into one Excel sheet. Disagreements between reviewers will be resolved by a third reviewer (AT). All extracted data will be reported on in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocol (PRISMA-P) guidelines.³⁵

Grey literature search

Grey literature will be searched from July 2021 to earliest available date following the Canadian Agency for Drugs and Technology in Health 'Grey Matters' framework.³⁶ Search terms will include 'quality indicators' and 'transition to adult care', and will be piloted for the first five databases included in the Grey Matters framework. Additionally, the National Institute for Health and Care Excellence, National Quality Forum and Agency for Health Research and Quality databases will be hand-searched with more extensive search terms for reports and/or guidelines identifying indicators for transition. Two separate reviewers will complete the grey literature search and record findings in the checklist provided by grey matters (KB and LL). The data abstraction form will be modified for the grey literature search.

Study appraisal

Studies will be critically appraised using a modified version of the Appraisal of Guidelines for Research and

Table 1 Information to be extracted from studies included in systematic review

Category	Data to be extracted
Study information	<ul style="list-style-type: none"> ▶ Author(s) ▶ Title of article ▶ Year ▶ Country of origin
Study methodology	<ul style="list-style-type: none"> ▶ Study design ▶ Population ▶ Sample size ▶ Panel characteristics (ie, expert vs patient panels; paediatric vs adult providers) ▶ Data collection method ▶ Clinical context/disease
Quality indicators	<ul style="list-style-type: none"> ▶ Description of indicator ▶ Indicator category (illness-specific vs non-illness specific) ▶ Indicator level (ie, patient, caregiver, provider, health system) ▶ Classification according to Donabedian model (ie, structure, process, outcome) ▶ Classification according to Institute of Medicine domain of healthcare quality (ie, patient-centred, effective, efficient, safe, timely, equitable) ▶ Information for measurement of quality indicator (eg, instructions for use, frequency/interval of measurement, tools for measurement) ▶ Associated evidence for quality indicator

Evaluation II instrument for Quality Indicators (AGREE II-QI).³⁷ The AGREE II-QI tool has been previously used to evaluate the development of quality indicators.^{38 39} Evaluation of the process used to develop quality indicators will be based on six domains: scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability and editorial independence. Degree to which quality indicators meet domain items will be rated on a 7-point Likert scale (1='strongly disagree'; 7='strongly agree'). The AGREE II-QI instrument will be piloted for the first two included studies to assess utility of the tool in the context of this systematic review. Two independent reviewers will complete the critical appraisal for all included studies (KB and LL). Ratings will be compiled into a Microsoft Excel spreadsheet and domain scores will be calculated in accordance with the scoring system outlined in the AGREE II user manual.³²

Summarising results

Study characteristics recorded in the data extraction form will be presented in a table, following PRISMA-P guidelines. Extracted quality indicators will be organised into a conceptual framework with illness-specific and non-illness specific categories. Indicators will be further subcategorised into (1) patient, (2) caregiver, (3) provider and (4) health system-level. The Donabedian model and the Institute of Medicine (IOM) Domains of Healthcare Quality are two well-established quality measurement frameworks which will be used to classify identified quality indicators.^{26 40–42} According to the Donabedian model, quality indicators will be classified as structure (ie, metrics assessing the characteristics of the care setting, such as human resources, models of care and availability of services), process (ie, metrics assessing the delivery of care, including patient education, counselling, diagnosis and treatments) or outcome (ie, metrics assessing the effect of healthcare services on the health of the patients and is frequently).^{26 40 41 43} Using the IOM Domains of Healthcare Quality, quality indicators will be classified as patient-centred (ie, ensures patient values guide clinical decisions), equitable (ie, provides high-quality care to all, regardless of personal characteristics), efficient (ie, avoids waste), effective (ie, practices evidence-based medicine), safe (ie, avoids harm) and timely (ie, reduces wait times and delays in receiving care).^{42 44} Classifying quality indicators by these frameworks will allow us to identify any potential gaps in measurement (ie, identify any missing categories of indicators, disproportionate number of indicators in certain categories). It is expected this framework will evolve as indicators are identified through the review, and changes will be made accordingly.

Patient and public involvement

The principal investigator of this systematic review, AT, is cochair of a Canada-wide Quality Indicators in Transition Subcommittee of Children Healthcare Canada's Health Hub in Transition.¹⁰ This network was founded in 2019 and aims to collaborate with stakeholders across

the continuum of healthcare delivery to coordinate the services provided during transition to adult care. Committee membership includes representative national stakeholders, including patients, caregivers, health leaders and multidisciplinary healthcare providers with diverse geographical representation and cross-condition expertise (eg, physical, mental and developmental conditions). The Health Hub in Transition is driven by conducting research informed by the needs of patients and caregivers.¹⁰ Throughout the development of this systematic review, the research team has been continually seeking input from committee members on study objectives and knowledge translation activities. As results are identified, the research team will continue to consult the committee to refine the conceptual framework.

DISCUSSION

This review will identify quality indicators for transition to adult care for adolescents with chronic physical and/or mental illnesses. Consensus on which quality indicators are needed to measure transition success is necessary to ensure comprehensive evaluation of patient and system-level outcomes.

Few studies have identified which measures of transition success matter to adolescents with chronic illnesses. A qualitative meta-synthesis highlighted youth expectations of successful transition, including transition readiness, transition education and independence.⁴⁵ While research has suggested adolescents and their caregivers have different priorities and needs from their clinicians, the majority of existing quality indicators have been proposed exclusively by healthcare providers.^{12 46–48} A recent Delphi survey engaged patients, caregivers and healthcare providers to identify core components of successful transition from paediatric to adult mental health services.⁴⁹ However, these findings cannot be generalised to reflect the priorities of patients with chronic physical illnesses and their caregivers. Further, a study found indicators of transition success (eg, lost to follow-up, trust with adult provider) were partially related to patient-reported outcomes (eg, adherence to therapeutic regimen, disease-related self-efficacy).⁵⁰ Without incorporating patient and caregiver perspectives in the development of quality indicators, it is difficult for health leaders, administrators and clinicians to benchmark, evaluate or compare transition processes and outcomes across conditions and jurisdictions.

Quality indicators in transition need to reflect the complexity of patient care needs, their strengths and capture both clinical and process outcomes. Social determinants of health, patient-reported outcomes and health literacy will also be prioritised within the framework we build based on the available evidence. We hope to work alongside health leaders and administrators to elevate the transition platform and identify and leverage funding opportunities to support needed transition work. In addition, our review will help inform more specificity and a

minimum standard required for transition to adult care among healthcare accreditation agencies.

Although this systematic review will highlight the perspectives of key stakeholders in transition to adult care, there remain potential limitations to this approach. Notably, limiting inclusion of quality indicators to development through consensus-building methods may reduce the scope of indicators included in the review. Several studies, including quality improvement initiatives and evaluation of transition interventions, have developed quality indicators via non-consensus building methods (eg, literature review, one-on-one interviews) and will not be captured in this systematic review. Our review is only limited to literature in English language.

ETHICS AND DISSEMINATION

Ethics approval is not required by our institution for this study as this systematic review will synthesise findings from published literature. Results of this systematic review will be submitted for publication in a peer-reviewed journal. Additionally, abstracts will be submitted for oral and/or poster presentations. Findings will be disseminated to national stakeholders, including healthcare providers, patients and caregivers, through a Canada-wide collaborative, Health Hub in Transition, to gain insights into next steps and knowledge translation activities.

Quality indicators identified will be prioritised in a Delphi process with healthcare providers, patients and caregivers. Results will be used to develop a set of universal quality indicators for assessing transition. It is hoped this review will contribute to the development of best practices for measuring healthcare performance and provide a framework for evaluating quality improvement initiatives in transition to adult care.

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