

Pediatric to Adult Transition in Inflammatory Bowel Disease: Consensus Guidelines for Australia and New Zealand

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Background: The incidence of pediatric inflammatory bowel disease (IBD) is rising, and there is an increasing need to support adolescents when they transition to adult care. Evidence supports the use of a structured transition process but there is great variation across Australasia. The study aim was to develop evidence and expert opinion-based consensus statements to guide transitional care services in IBD.

Methods: A modified UCLA-RAND methodology was employed to develop consensus statements. An IBD expert steering committee was formed and a systematic literature review was conducted to guide the drafting of consensus statements. A multidisciplinary group was formed comprising 16 participants (clinicians, nurses, surgeons, psychologists), who anonymously voted on the appropriateness and necessity of the consensus statements using Likert scales (1 = lowest, 9 = highest) with a median ≥ 7 required for inclusion. Patient support groups, including direct input from young people with IBD, informed the final recommendations.

Results: Fourteen consensus statements were devised with key recommendations including use of a structured transition program and transition coordinator, mental health and transition readiness assessment, key adolescent discussion topics, allied health involvement, age for transition, and recommendations for clinical communication and handover, with individualized patient considerations. Each statement reached median ≥ 8 for appropriateness, and ≥ 7 for necessity, in the first voting round, and the results were discussed in an online meeting to refine statements.

Conclusions: A multidisciplinary group devised consensus statements to optimize pediatric to adult transitional care for adolescents with IBD. These guidelines should support improved and standardized delivery of IBD transitional care within Australasia.

Lay Summary

Transitional care practices for adolescents with inflammatory bowel disease vary across Australasia, and a need for standardized care has been identified. A multidisciplinary team developed Consensus Guidelines to facilitate standardized transition from the pediatric to adult healthcare setting across Australasia.

Key Words: inflammatory bowel disease, children, transition, practice guideline

Introduction

The process of transition for adolescents with chronic health conditions involves the gradual, planned transfer of care from the pediatric to the adult healthcare team.¹ The period of transition is an important yet challenging time period, shown to be crucial to the well-being of adolescents with chronic conditions and their carers.^{2,3} The process of transition comes with high expectations of health autonomy for the adolescent, characterized by the development of self-management, self-efficacy, and self-advocacy, requiring

many additional skills to meet these expectations such as communication, decision making, and assertiveness.^{4–6} For adolescents with inflammatory bowel disease (IBD), additional challenges are present related to their condition. Modifiable factors shown to affect transition success for adolescents with IBD include disease activity, treatment adherence, nutritional status, and the management of extra-intestinal manifestations or other comorbidities.^{3,7–9} In addition, appropriate consideration needs to be given to the transition of care for other issues of importance to the

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Key Messages

- What is already known? Transitional care for adolescents with inflammatory bowel disease varies across Australia and New Zealand, with structured transition shown to lead to better outcomes.
- What is new here? A multidisciplinary team developed a set of evidence-based and consensus guidelines to inform clinical practice throughout Australasia, taking into account regional variation and cultural diversity, for adolescents with inflammatory bowel disease.
- How can this study help patient care? Implementing guidelines for use across Australasia may be used to inform policy change and clinical practice, thus standardizing care and optimizing outcomes for adolescents.

adolescent, including mental health, education, and psychosocial stressors.^{3,10} The transfer of such complex care needs is also occurring in the context of change of healthcare delivery and important psychosocial milestones (including education and vocation). Inherent differences between the family-oriented, holistic, and triadic relationship of the pediatric-focused environment and the individualistic, autonomous environment of the adult healthcare service may make this process overwhelming.^{2,11,12}

Within the Australian and New Zealand context, there is considerable variability in the types of healthcare models available for transition care in IBD, as demonstrated by a survey of pediatric gastroenterologists across the region.¹³ This study reported that while the majority of respondents had access to a dedicated outpatient transition clinic for adolescents with IBD, there was otherwise significant variation in the transition process.¹³ Findings of the survey demonstrated variation in the age at which the transition process is commenced, the processes that are transferred during transition clinics, patient communication needs, formal assessments, and the infrastructure required for effective transition. Similarly, in adult gastroenterology, there is variability in the way in which healthcare is delivered, relating to the funding model of public vs private practice, as well as the location in which it is provided. A significant proportion of patients reside in the rural or regional setting, often with resultant limited access to services such as specialized radiology, colorectal surgeons, and the wider multidisciplinary team.^{14,15}

In a recent needs assessment survey carried out among pediatric gastroenterologists, the minority utilized formal transition guidelines to inform their transition practice, with the majority being of the opinion that formal Australasian guidelines would be beneficial.¹³ Accordingly, a need to standardize IBD transition care across Australia and New Zealand was recognized, prompting the commencement of a transition consensus statement development process. This is on the background of other countries/organizations conducting similar processes.¹⁶⁻¹⁹ Given the unique aspects of Australia and New Zealand, especially in the diversity of geography, it was considered important to develop standards that considered local aspects of IBD care. The aim of this study was to develop a consensus guideline to facilitate standardized transition for adolescents with IBD from pediatric to adult care throughout Australasia.

Methods

Definitions

Transition was defined as the process of moving from pediatric to adult healthcare services. This includes initial planning, the actual transfer between services, and the services throughout the period.²⁰

Transfer of care was defined as the point when there was a shift in responsibility from pediatric to adult centers, with subsequent care only being provided by the adult center.²⁰

Development Process

The modified RAND/UCLA Appropriateness Method (RAM) was utilized throughout the consensus process.²¹ The RAM is a modified Delphi process that incorporates multiple voting rounds to determine the appropriateness, necessity, and face validity of statements developed relating to a specific topic. The following stages were followed as part of completing the RAM for transition guideline development for adolescents with IBD (Figure 1).

Steering committee

An Australasian steering committee was formed, based on clinical and academic expertise in pediatric to adult IBD transition care, to guide the development of the consensus statements. Members comprised a pediatric gastroenterologist (E.G.), adult gastroenterologist consultants and advanced trainee (A.J.W., B.C., P.C.), Pediatric Gastroenterology Research Fellow (A.V.R.), and an Agency of Clinical Innovation representative (R.H.). Gastroenterology Society of Australia representation was provided with involvement of the IBD faculty lead (B.C.).

The New South Wales (NSW) Agency for Clinical innovation is the lead agency for innovation in clinical care in NSW. The Transition Care Network works with clinicians, young people, families, and carers to improve continuity of care for young people (14-25 years of age) with chronic health conditions in NSW as they move from pediatric to adult health services.

Literature review

A systematic review of literature concerning transition care in IBD was undertaken to identify studies reporting on transition interventions for adolescents with IBD.²² This review adhered to guidelines outlined in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement,²³ and was registered in the PROSPERO under the identification number CRD42023380846. The search encompassed the databases EMBASE, PubMed, CINAHL, and CENTRAL. The search employed MeSH (Medical Subject Headings), alternative wording, free text, and truncation terms relating to the topics: transition, transitional care, pediatrics, young adult, adolescents, inflammatory bowel disease, ulcerative colitis, and Crohn's disease. Of the search results, 29 articles meeting the inclusion criteria were identified. Details regarding study populations, transition intervention components, and efficacy for medical and transition-related outcomes were extracted and evaluated. While there was significant heterogeneity among the studies and the reported interventions, the extracted data were synthesized to provide guidance on the elements of transition programs found to be effective among this population.²² These elements were utilized to formulate initial statements, and when applicable, evidence was

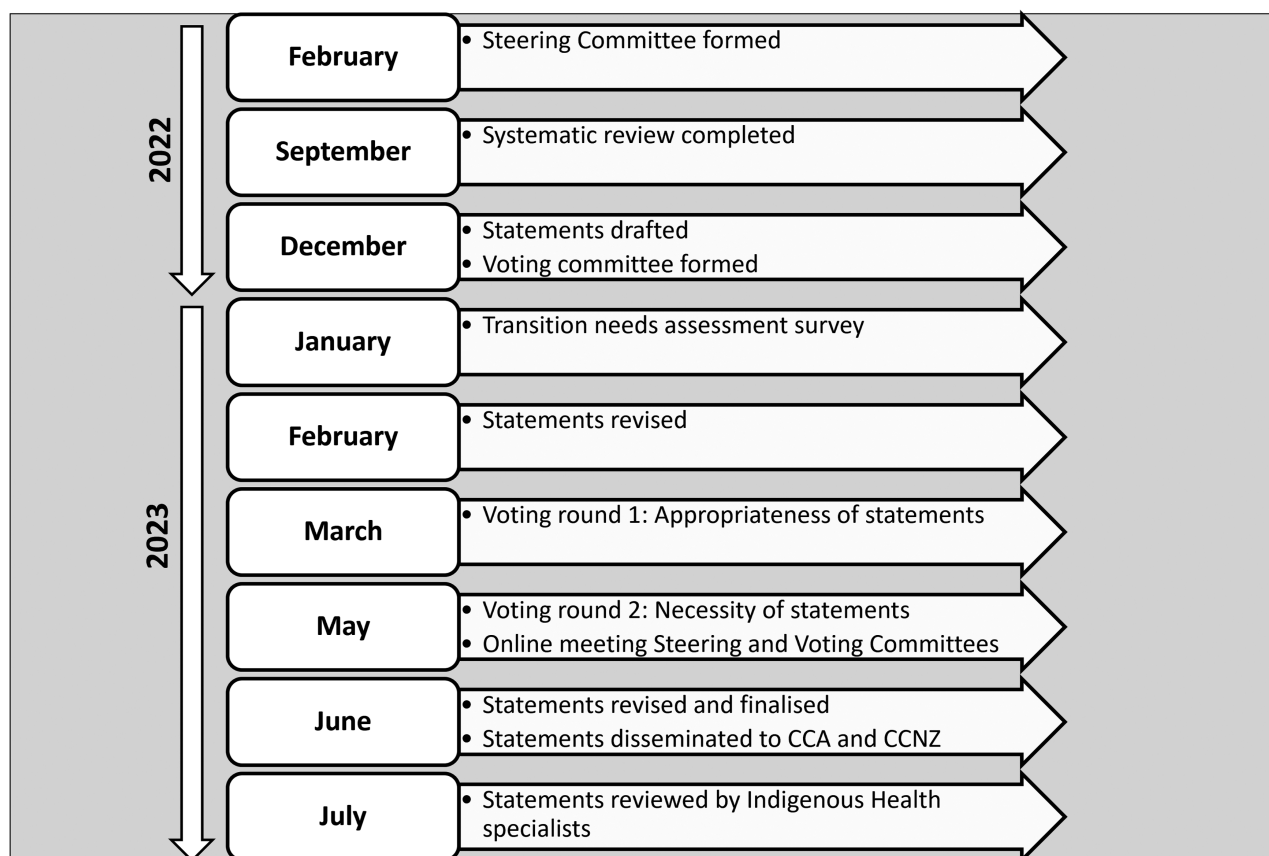


Figure 1. Timeline of the consensus statement development process. CCA, Crohn's and Colitis Australia; CCNZ, Crohn's and Colitis New Zealand.

assessed using the GRADE (Grading of Recommendations, Assessment, Development and Evaluation) rating system.²⁴ Ratings were assigned based on the quality of evidence (high = A, moderate = B, low = C, very low = D) and strength of recommendation (strong evidence for/against = 1, weak evidence for/against = 2).²⁴ The GRADE rating for evidence in support of each statement is included where the assessment was possible.

Statement Generation

Consensus statements were drafted with utilization of the key findings of the systematic review,²² the outcomes of the needs assessment survey,¹³ the Crohn's Colitis Australia (CCA) Audit 2016 recommendations,¹⁴ and the clinical expertise of the steering committee.

Voting committee

A multidisciplinary voting committee was formed, by invitation from the steering committee, to provide voting and feedback for the consensus statements (named in Acknowledgements section). This group comprised pediatric and adult specialists, with consideration of employment role and location to ensure comprehensive representation of geographically diverse multidisciplinary teams. Committee member roles comprised:

- Adult gastroenterologists (3): 2 from Australia and 1 from New Zealand

- Pediatric gastroenterologists (2): 2 from Australia and 1 from New Zealand
- Adult IBD nurses (3): 2 from Australia and 1 from New Zealand
- Pediatric IBD nurse (1): Australia
- Pediatric transition nurse specialist (1): New Zealand.
- Psychologist (1): Australia
- Colorectal surgeon (1): Australia
- Pediatric surgeon (1): New Zealand
- Adolescent medicine physicians (2): 1 from Australia, 1 from Tasmania

Voting rounds

Two rounds of anonymous, online voting were carried out by the voting committee in accordance with the modified RAM method that stipulates the scoring, format, and order of the voting rounds, and the guidelines provided to voting committees.²¹ Prior to each voting round, all voting committee members were sent the summarized results of the literature review used to develop each statement and instructions of how the voting round was to be conducted. Voting committee members were asked to first rate the appropriateness of each statement using their own clinical judgment, as opposed to what they perceive that other experts may think.²¹ They were also asked to consider each statement as relating to an average patient presenting to an average physician who practices in an average hospital, and they were specifically instructed not

to consider cost implications in their judgments.²¹ All voting committee members could also provide free text feedback on each statement, as well as on the guidelines overall.

Appropriateness voting

The first voting round was to consider appropriateness of each of the consensus statements as they relate to the transition of care for adolescents with IBD. Statements were to be considered appropriate if the expected health benefit exceeded the expected negative consequences by a sufficiently wide margin that the action resulting from the statement is worthwhile. This voting round was to determine whether the voting committee perceived that each individual statement was congruent with their own expectations and experience of the transition process for adolescents with IBD, and whether each would likely be advantageous to include in the overall guideline.

Necessity voting

The second voting round was to consider necessity of the consensus statements as they relate to the transition of care for adolescents with IBD. A statement was considered necessary provided that it had been rated as appropriate, and when it could be considered improper care not to provide the recommendation, and provided that there is a reasonable chance that this recommendation would meaningfully benefit the patient. This voting round was to gauge whether each statement was considered an essential component of the transition process by the voting committee members and should be included in the guidelines.

Each individual statement was rated on a scale of 1 to 9 in both voting rounds, with a score guide of 1 indicating that the statement is highly inappropriate/unnecessary, a score of 5 indicating that the statement is uncertain, and a score of 9 indicating that the statement is highly appropriate/necessary.

Vote scoring

The scoring process was carried out as defined in the RAM manual for when the voting panel contains 14 to 16 members.²¹ A median score, with interquartile range, was calculated for all respondents in each of the 2 voting rounds, with the following definitions applied to determine an overall rating:

- Appropriate/necessary: panel median of 7 to 9, without disagreement
- Uncertain: panel median of 4 to 6 OR any median with disagreement
- Inappropriate/unnecessary: panel median of 1 to 3, without disagreement
- Agreement: ≤ 4 panelists rating the statement outside the 3-point region (1-3; 4-6; 7-9) containing the median
- Disagreement: ≥ 5 panelists rate the statement at each of the extreme ends of the scale (1-3; 7-9)

Meetings

Following completion of both voting rounds, the steering and voting committees participated in a 2-hour online meeting to discuss the statements in further detail as well as the voting results. For this meeting the final consensus statements were presented according to appropriateness, necessity, grade of evidence, and strength of recommendation. Face validity of

each statement was discussed, and recommended revisions were made with agreement by all.

Patient/consumer input

The Australasian patient support organizations of CCA and Crohn's and Colitis New Zealand (CCNZ) were approached to consider providing feedback on the consensus statements. The requested feedback was 2-fold: both from CCA/CCNZ members of staff, scientific advisory board, or board members, with a view to endorsing the statements via their organizations, and consumer feedback from a group of adolescent and young adults (AYAs) with IBD.

Indigenous Peoples input

The consensus statements were shared with specialists in indigenous health to determine if additional considerations should be included in the guidelines, specific to patients who identify as Aboriginal or Torres Strait Islanders in Australia and who identify as Māori in New Zealand. Specialists were based at the Aboriginal Health and Medical Research Council of New South Wales, Australia, and the Department of Māori Indigenous Health Innovation, University of Otago, Christchurch, New Zealand.

Results

Final Consensus Statements

The final versions of the transition consensus statements were agreed by all steering and voting committee members (Table 1).

Voting Results

Sixteen multidisciplinary team members from across Australia and New Zealand participated in the consensus statement voting process, all of whom were external to the steering committee.

Appropriateness

The initial voting round to determine appropriateness of each of the 14 statements was completed by all 16 voting committee members. While the median score for all statements was ≥ 8 , the range of scores were variable (Figure 2). When the predefined parameters to assess agreement/disagreement were applied, 12 statements met the criteria of appropriate and 2 were determined as uncertain based on the number of panel votes outside the 3-point region of the median (Table 2).

Necessity

The voting round to determine necessity of the 14 statements was completed by all 16 voting committee members. The median score for all statements was ≥ 7 , although variation in scores was seen once again (Figure 2). The ratings assigned to the categories of agreement/disagreement resulted in 11 statements meeting the criteria of being necessary and 3 uncertain based on the number of panel votes outside the 3-point region of the median (Table 3).

Given that there was majority agreement for both appropriateness and necessity on the first rounds, there were no subsequent voting rounds. However, an online meeting was held between the steering and voting committees to discuss all statements with a particular focus on those with overall ratings deemed uncertain (Tables 2 and 3).

Table 1. Final consensus statements to guide transition of children with inflammatory bowel disease in Australasia.

Number	Statement
1	A structured transition program is recommended for adolescent and young adults with inflammatory bowel disease.
2	A transition program should develop and assess relevant skills including disease-related knowledge, self-efficacy, decision making, and transition readiness.
3	Validated tools are recommended during the assessment of transition-related skills.
4	Mental health screening should be incorporated into the transition model.
5	The optimal start time and duration of transition is not well defined but should be individualized.
6	The transition model should be designed to be appropriate to the individual circumstance of the patient.
7	The use of a transition coordinator improves transition-related outcomes and is considered an integral component of a transition program.
8	Transition programs should incorporate access or referral pathways to relevant allied health professionals including a psychologist, social worker, and dietitian.
9	A joint clinic between the pediatric and adult gastroenterologists during the transition process should be facilitated on at least 1 occasion.
10	Written medical handover must accompany each patient and include disease history, prior medication exposures, and other relevant past medical and social history.
11	The provision of age-appropriate communication, information, and resources is recommended.
12	The discussion of age-appropriate psychosocial and lifestyle issues is recommended during the transition process.
13	Inpatient and outpatient care of adolescents in adult hospitals should occur in an age-appropriate environment.
14	The transition process generally needs to include communication regarding the transfer of clinical management to the patient from the carer.

Additional Feedback

Voting committee

The voting committee were encouraged to provide free text feedback for each statement during the voting process. These were collated, reviewed, and incorporated into the discussion for each statement where appropriate (Supplementary Table 1).

Patient/Consumer Input

Feedback from CCA/CCNZ on the consensus statements was provided by 6 adults who are members of staff, the scientific advisory board, or board members. In addition, feedback was provided by 5 AYAs with a range of time since diagnosis of 2.5 to 7 years and an age range of 17 to 24 years.

The CCA/CCNZ feedback provided overall strong agreement with the recommendations, although there was concern about resource availability for some of the statements (Supplementary Table 1). Stakeholder feedback is highlighted for each statement where appropriate.

Indigenous Peoples Input

There was universal support of the guidelines from the indigenous health specialists consulted as part of the development process. The feedback received emphasized the importance of primary care clinicians in the transition process to ensure continuity of care for patients. It was also recommended to provide details of the indigenous health advisors working in the adult care center to the adolescent (where available), or to facilitate contact between the 2 parties. This would help indigenous adolescents to learn how to communicate, and establish, their need for a culturally safe environment and maximize their opportunities for achieving health equity.

Statements

The individual consensus statements are presented in the following sections, each with an accompanying GRADE of evidence from the literature review, discussion based on literature, consumer and organization feedback, and recommendations based on the needs assessment survey. A final paragraph for each statement was constructed to aid with implementation in clinical practice. Furthermore, a checklist for implementation is provided in the Supplementary Material (Supplementary Table 3).

Statement 1

A structured transition program is recommended for AYAs with IBD.

Grade of evidence: B1

Agreement rating: Appropriate, necessary

There was very broad consensus in both appropriateness and necessity for a structured transition program in IBD across Australasia. The survey of current practice across the region showed that many centers do have such a program.¹³ The consensus group was informed by evidence that demonstrated that such a program improves disease-specific and transition-related outcomes and is cost-effective.^{25,26} Indeed, many countries and regions now have their own guidelines for transition of patients with IBD^{16,19,27} or patients with gastroenterological conditions more generally.^{28,29} Young people with IBD highlighted the importance of this process being centered on the patients themselves, educating them on the responsibility of disease management, rather than their carer givers or indeed the system. This was also highlighted by the consensus panel, who focused on the importance of consumer investment into the process.

Implications for clinical practice: Design and implementation of a structured transition program is best facilitated by a multidisciplinary team, with regular obtainment of feedback and assessment of outcomes associated with transition to further refine the program. Transition focused organizations such as the Agency for Clinical Innovation³⁰ can provide support, either through consultancy or transition case managers. Transition support services and government led transition or youth health networks can provide support and advice on implementation. Regional IBD services may also seek local guidance on how transition support services are structured and implemented.

Statement 2

A transition program should develop and assess relevant skills including disease-related knowledge, self-efficacy, decision making, and transition readiness.

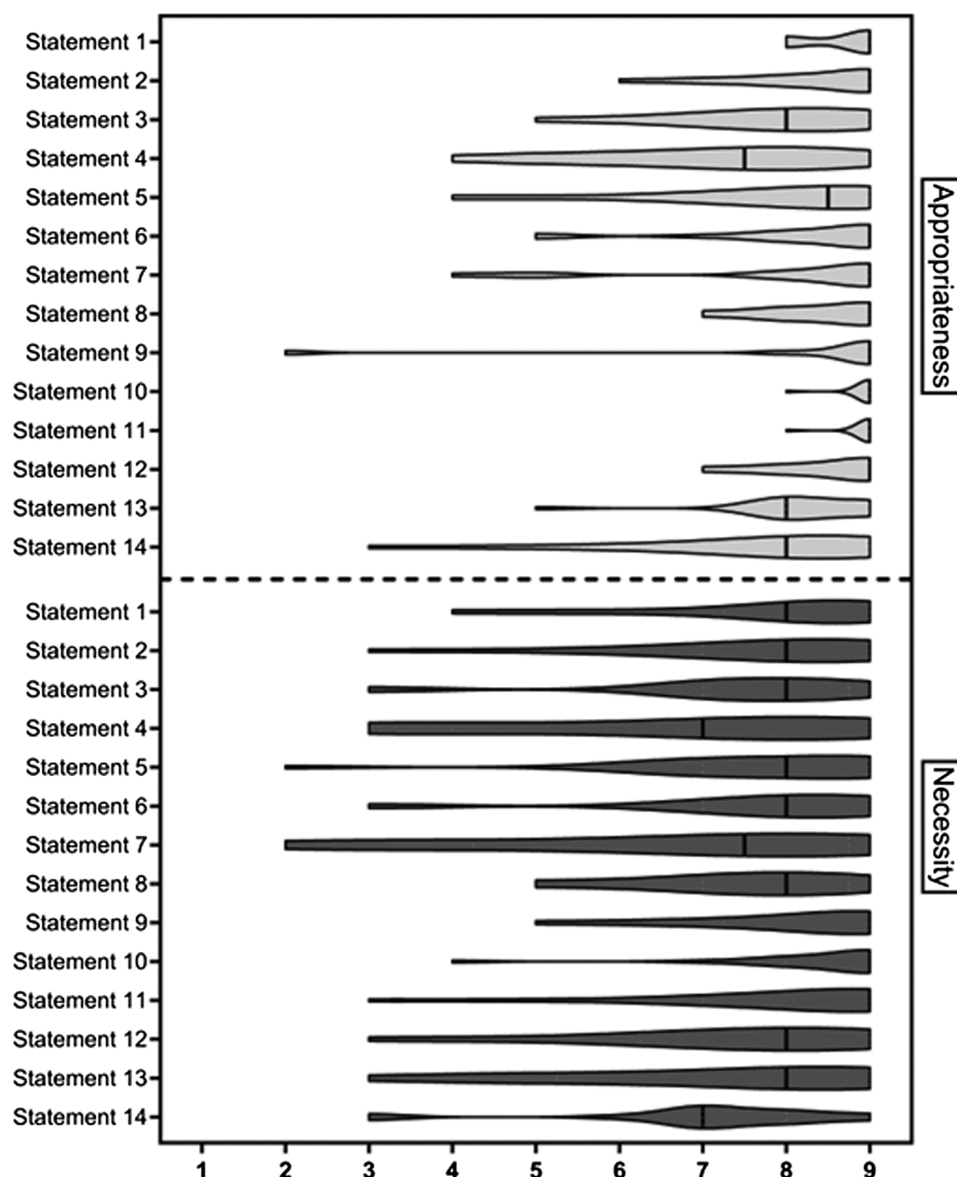


Figure 2. Voting score results for appropriateness and necessity of the 14 consensus statements. Shape width is an indication of score frequency, shape ends are lower/upper range, and the solid line is the median.

Grade of evidence: C1

Agreement rating: Appropriate, necessary

Adult gastroenterologists consider barriers to successful transition for adolescents with IBD as being deficiencies in knowledge of their own medical history/treatment, knowledge of disease characteristics, independent functioning, self-advocacy, and care coordination.^{6,31-33} Unfortunately, knowledge and self-management deficiencies in adolescents with IBD are common, with literature reporting deficits on the topics of disease characteristics, medication side effects and dosages, and the impact of smoking.³⁴⁻³⁶ With regard to self-management skills, or readiness to transition, adolescents with IBD are falling short on scheduling and keeping track of their own appointments, traveling independently to appointments, attending appointments, and refilling prescriptions without the help of a parent or carer.³⁷⁻³⁹

For adolescents with IBD, the acquisition of health knowledge concerning their own diagnosis and disease management

is integral to their treatment adherence and development of self-management skills and health autonomy.^{5,40-42} Disease knowledge should include, in concordance with the literature, disease characteristics (diagnosis, disease location and extent, surgical history), medication history (current and previous regimens, including adverse effects), natural history of IBD, the role of disease monitoring procedures and investigations, and the importance of preventive health.^{18,43-45} Several observational studies utilizing short educational interventions demonstrated their utility in improving disease-related knowledge scores. These include the use of educational videos, a health summary card, and an IBD pocket guide.⁴⁶⁻⁴⁸

Crucial self-management skills that are required for achieving transition readiness are considered to be knowledge of disease and own history (including knowledge-seeking behavior); medication adherence; booking, attending, and engaging in appointments; refilling prescriptions; self-monitoring of symptoms; lifestyle modifications; compliance

Table 2. Results of the voting round for appropriateness of all 14 proposed statements.

Statement	Topic	Median (IQR)	Ratings within a 3-point region of the median (N = 16)	Ratings at the extreme end of scale (1-3) (N = 16)	Overall rating
1	Structured transition program	9 (8-9)	16 (100)	0	Appropriate
2	Transition readiness assessments	9 (8-9)	15 (94)	0	Appropriate
3	Use validated assessment tools	8 (7-9)	13 (81)	0	Appropriate
4	Mental health assessment	8 (6-8)	11 (69) ^a	0	Uncertain
5	Start/duration of transition process	9 (7-9)	11 (69) ^a	0	Uncertain
6	Individual circumstance	9 (8-9)	14 (88)	0	Appropriate
7	Transition coordinator	9 (8-9)	12 (75)	0	Appropriate
8	Allied health professional involvement	9 (8-9)	16 (100)	0	Appropriate
9	Structured transition clinic	9 (8-9)	14 (88)	0	Appropriate
10	Written handover	9 (9-9)	16 (100)	0	Appropriate
11	Information resources	9 (8-9)	16 (100)	0	Appropriate
12	Psychosocial/lifestyle discussion	9 (8-9)	16 (100)	0	Appropriate
13	Environment for transition	8 (8-9)	15 (94)	0	Appropriate
14	Communication during transition	8 (7-9)	13 (81)	1 (6)	Appropriate

Values are n (%), unless otherwise indicated. Agreement was defined as a ≤ 4 rating outside the 3-point region containing median. Disagreement was defined as a ≥ 5 rating at each extreme end of the scale.

^aIndicates a result leading to an overall rating of uncertain.

with instruction and medical procedures; and self-care (eg, stoma care).⁴⁹⁻⁵¹

The expert voting committee and patient support groups (CCA/CCNZ) raised the issue that carrying out assessments of knowledge/transition readiness may be time-consuming (Supplementary Table 1). However, it was concluded that assessments were important to identify deficits, provided that patient burden was minimized. Youth with IBD were less likely to endorse the use of assessments, but they did acknowledge that they may enable the patient to be more independent and help them communicate with their adult healthcare team.

Implications for clinical practice: Assessments can be incorporated into transition programs through paper-based or electronic modalities, including through integration through electronic medical records, such as Crohn's Colitis Care (refer to statement 10 for further detail). It is important to ensure that assessments are tailored to suit the educational and maturation level as well as interest of the young adult. Serial assessment is recommended, at the commencement of and during transition and then following the transfer of care. Educational initiatives in addition to patient support tools can be useful approaches to aid with overcoming recognized deficiencies in self-management skills.^{33,52}

Statement 3

Validated tools are recommended during the assessment of transition-related skills.

Grade of evidence: C1

Agreement rating: Appropriate, necessary

It is widely considered that all adolescent IBD patients should have assessments of their disease knowledge and self-management skills/readiness to transition,⁵³ as their disease management may be adversely affected by gaps or misconceptions in either. The most efficient way to assess these metrics are with validated tools that are appropriate for the target population, used to quantify understanding

or skills ability. In using validated tools, longitudinal change can be monitored, as well as assessing response to targeted interventions.

Opinions from voting committee members on this statement were that providing named tools would be helpful. They also highlighted that is also important for clinicians to build on, and assess, these metrics (knowledge, readiness to transition) informally during their time with adolescents in clinic. Youth with IBD were reluctant to have formal assessments carried out, as they may be perceived as a test, or be stressful, but having the assessments and their benefit defined were important factors, and the language used around delivery of such tools should minimize the perception of formal testing.

Implications for clinical practice: Validated tools that have been developed for use in the pediatric/adolescent population are provided as recommendations in Table 4.

Statement 4

Mental health screening should be incorporated into the transition model.

Grade of evidence: D1

Agreement rating: Uncertain appropriateness, uncertain necessity

There is increasing recognition of the mental health needs of adolescents in the general population, with reported rates of 25% of Australian youth engaged with mental health services.⁶⁹ Within the Australasian IBD population, there has been the reporting of higher rates of mental illness, with rates of 35% of transitioning adolescents having mood disorders⁷⁰ and recent data reporting up to 61% experiencing psychological distress.⁷¹ Further compounding the risks of mental illness within the IBD adolescent population is the potential negative impact of transition of care from pediatric to adult services. There has been recognition that mental illness can adversely impact transition in IBD, with the number of mental health diagnoses and overall psychological well-being negatively

Table 3. Results of the voting round for necessity of all 14 proposed statements.

Statement	Topic	Median (IQR)	Ratings within a 3-point region of the median (N = 16)	Ratings at the extreme end of scale (1-3) (N = 16)	Overall rating
1	Structured transition program	8 (7-9)	13 (81)	0	Necessary
2	Transition readiness assessments	8 (7-9)	13 (81)	1 (6)	Necessary
3	Use validated assessment tools	8 (7-9)	14 (88)	2 (13)	Necessary
4	Mental health assessment	7 (4-9)	10 (63) ^a	3 (19)	Uncertain
5	Start/duration of transition process	8 (7-9)	14 (88)	1 (6)	Necessary
6	Individual circumstance	8 (7-9)	14 (88)	2 (13)	Necessary
7	Transition coordinator	7.5 (4-9)	10 (63) ^a	3 (19)	Uncertain
8	Allied health professional involvement	8 (7-9)	14 (88)	0	Necessary
9	Structured transition clinic	9 (7-9)	14 (88)	0	Necessary
10	Written handover	9 (8-9)	15 (94)	0	Necessary
11	Information resources	9 (7-9)	14 (88)	1 (6)	Necessary
12	Psychosocial/lifestyle discussion	8 (6-9)	12 (75)	1 (6)	Necessary
13	Environment for transition	8 (5-9)	11 (69) ^a	1 (6)	Uncertain
14	Communication during transition	7 (7-8)	13 (81)	2 (13)	Necessary

Values are n (%), unless otherwise indicated. Agreement was defined as a ≤ 4 rating outside the 3-point region containing median. Disagreement was defined as a ≥ 5 rating at each extreme end of the scale.

^aIndicates a result leading to an overall rating of uncertain.

correlating with transition readiness.⁷² Accordingly, screening of mental health during the transition period is encouraged. Suggested screening tools include the depression, anxiety, and stress scale (DASS-21), 10-item Kessler Psychological Distress scale (K10), or home environment, education and employment, eating, peer-related activities, drugs, sexuality, suicide/depression, and safety from injury and violence scale (HEEADSSS) (Table 4).⁶⁵⁻⁶⁸

When transition care models were reviewed,²² it was identified that the role of a psychologist was integrated into only 2 of 23 published transition care studies.

Accordingly, there may also need to be the consideration of online resources, particularly while awaiting formal mental health assessment and management. It is also important that the assessment and delivery of mental health screening and management is delivered in an age-appropriate format by professionals who have training and experience in adolescent mental healthcare. Empowering adolescents to focus on positive aspects of their lives as opposed the challenges is another approach that can be considered in routine clinical encounters. It is important to include the primary care provider/general practitioner (GP) in the mental health referral process, especially if there is a role for activation of a mental healthcare plan.

Implications for clinical practice: There is a recommendation for mental health screening of adolescents transitioning between pediatric to adult care, at the time of transfer of care, as well as during their subsequent care. In the event of the recognition of concerns through screening, referral to available mental health services is recommended with consideration of establishing a mental healthcare referral pathway, acknowledging the limitations to access in many regions or service models.

Statement 5

The optimal start time and duration of transition is not well defined but should be individualized.

Grade of evidence: D1

Agreement rating: Uncertain appropriateness, necessary

There is no set age that transfer of care should occur for all patients with IBD. This will be influenced by factors such as age of diagnosis, availability of expertise, and local policies on admission to hospital and/or infusion centers. Transition (ie, the process of patients moving to adult-focused care), rather than the moment of transfer should, where possible, begin early in adolescence. The steering and voting groups generally suggested around the ages of 12 to 14 years for most young people, which is supported in the literature.⁷³ Clearly many patients will not be diagnosed until after this, and the combination of education around diagnosis and preparation for transition needs to be carefully balanced. The beginning of the transition process means beginning to explain the process and engaging more frequently directly with the patient themselves. Feedback from stakeholders and patients to this guideline certainly supported a more gradual process, with time to prepare for the change in circumstances (Supplementary Table 1).

If possible, transfer should occur during a period of disease remission,^{18,32} and was generally agreed to occur after puberty is complete, and at the end of secondary school.³¹ These later factors will vary from patient to patient and highlight the importance of flexibility and individualization of the transition program.

Implications for clinical practice: Each service should individualize the appropriate timing of both the initiation of the transition process, as well as the age at which transfer to adult services occurs. Factors influence this individualized process include disease activity, pubertal stage, and educational plans.

Statement 6

The transition model should be designed to be appropriate to the individual circumstance of the patient.

Grade of evidence: D1

Table 4. Recommendations of assessment tools for adolescents with IBD

Topic	Assessment tool	Description
General disease-specific knowledge tools	IBD-KID2 ⁵⁴	IBD-KID2 ⁵⁴ is a 15-item tool scored as 1 point for each correct answer, validated for children 8+ years of age. IBD-KID2 has also been reported as valid for use in the adult IBD population ⁵⁵ when compared with CCKNOW, ⁵⁶ so it provides a suitable crossover for the adolescent age group and has had sensitivity to change confirmed. ⁵⁷
	IBD-KNOW ⁵⁸	IBD-KNOW is a 24-item long assessment tool scored as 1 point for each correct answer, validated among youth and adults 16+ years of age. ⁵⁸ Validation was carried out against CCKNOW.
	RTT ⁵⁹	The RTT is a 27-item open-question format tool scored using a 4-stage point system and validated for use in adolescents with IBD 15+ years of age. ⁵⁹
Personal disease-specific knowledge tools	IBD KNOW-IT ⁶⁰	This is a 12-item tool validated among children 10+ years of age to assess knowledge of their own symptoms, medication regimen, disease monitoring, and medical team. ⁶⁰ IBD KNOW-IT was developed from the self-management checklist of the Improve Care Now network. ^{61,62}
	My Health Passport ³³	This tool is a personal disease record validated for accuracy for children 14+ years of age. ³³ My Health Passport allows adolescents with IBD to complete details about their own history, allowing them to carry a wallet-sized card containing relevant information. This is available as a free online tool (www.sickkids.on.ca/myhealthpassport).
Self-management skills/transition readiness tools	IBD-STAR ⁶³	IBD-STAR is an IBD-specific 18-item tool scored by allocation of responsibility for tasks and validated for children 10+ years of age. ⁶³
	TRAQ ⁵⁰	TRAQ is a 20-item transition readiness assessment tool scored by reports of skill level and validated for use by children 14+ years of age. ⁵⁰ While TRAQ is not IBD specific, it has been well used in the adolescent IBD population. ⁶⁴ It is available as a free online tool (https://www.etsu.edu/com/pediatrics/traq/).
Mental health	DASS-21 ⁶⁵	The DASS-21 evaluates the negative emotional states of mental health symptoms. This was developed among children 17+ years of age, but the simplicity of wording makes it feasible to administer in younger children (https://novopsych.com.au/assessments/depression/depression-anxiety-stress-scales-short-form-dass-21/).
	K10 ⁶⁶	This tool can be used to screen for psychological distress, such as anxiety or depression. The K10 has been validated for use in children and adolescents. ⁶⁷
	HEEADSSS ⁶⁸	HEEADSSS is the most recent version of the psychosocial interview for adolescents, with new questions relating to electronic media use in addition to the original critical stressors identification items.

Abbreviations: CCKNOW, Crohn's and Colitis Knowledge Score; DASS-21, 21-item Depression, Anxiety, and Stress Scale; HEEADSSS, Home environment, Education and employment, Eating, peer-related Activities, Drugs, Sexuality, Suicide/depression, and Safety from injury and violence; IBD, inflammatory bowel disease; IBD-KID2, IBD Knowledge Inventory Device version 2; IBD-KNOW, IBD Knowledge; IBD-STAR, IBD Skills Tasks and Activities Record; K10, 10-item Kessler Psychological Distress Scale; RTT, Rotterdam Transition Test; TRAQ, Transition Readiness Assessment Questionnaire.

Agreement rating: Appropriate, necessary

Given the vast geographic and demographic variation of Australia and New Zealand, as well as the different hospital and medical systems across national and state borders, there needs to be local variation in the most appropriate model for transition of IBD patients. Beyond local variation, patient factors, including family circumstances, comorbid diagnoses (especially behavioral and/or developmental issues), and patient preference should be considered. There are a much smaller number of pediatric centers with IBD expertise in Australasia than adult centers. Therefore, particularly in metropolitan areas, it is likely that there is more than 1 option for transfer of care.

A primary care provider (GP) should be identified prior to transition in patients with all chronic conditions.²⁰ Different adult (and indeed pediatric) IBD services will have differing shared-care arrangements with GPs. Nevertheless, transition is an important opportunity to ensure that the patient has a good relationship with their primary care provider, as they will be a source of continuity of care through the process and throughout their adult life. They also will have knowledge of other comorbidities, medications, and significant issues that may affect IBD care, and vice versa. This is also important, as

if the patient changes circumstances or wishes to change IBD service as an adult, the GP will hold the appropriate information to facilitate such a change.

For regional and remote patients, and even for those in metropolitan areas, virtual models for delivering a transition program are effective and can significantly reduce travel times and expense for patients.⁷⁴⁻⁷⁶

Implications for clinical practice: There needs to be flexibility in the transitional process for individual patients, including consideration of the role of telemedicine and the role of primary care provider.

Statement 7

The use of a transition coordinator improves transition-related outcomes and is considered an integral component of a transition program.

Grade of evidence: C1

Agreement rating: Appropriate, uncertain necessity

There is evidence to support the role of a transition coordinator in the transition process.⁷⁷⁻⁷⁹ There has been demonstration of improved transition readiness and higher rates of remission after implementation of an IBD transition

coordinator.⁷⁸ A designated and dedicated transition coordinator is essential in providing continuity of care for young people transitioning to adult care for a minimum of 12 months post-transition and until the young person is established in adult health services. An IBD specialist nurse would be ideal as a care coordinator but also a facilitator and relationship builder. They play a vital role in coordinating not only the pediatric and adult healthcare providers, but also the young adult and their parents and guardians.⁷ There has been the description of other allied healthcare professionals fulfilling the role as well, such as a clinical social worker.⁷⁸ In general, transition coordinators should have disease-specific knowledge in order to understand the needs of their patients through the process.²⁰ The transition coordinator has been involved in making an introductory phone call to facilitate the first visit with the adult healthcare provider,⁷⁰ in the formulation of a transition plan, in availability as the primary healthcare professional contact, and in ensuring that key milestones and progress are achieved.⁸⁰ This statement was widely discussed in the voting committee online meeting and also generated feedback responses from CCA/CCNZ (Supplementary Table 1). There was strong opinion from clinicians that the transition coordinator role is best allocated to the IBD nurse, with the benefits of this being focused on the importance of continuity of care. The agreement rating of being appropriate but of uncertain necessity relates specifically to concern over resource availability, and the possibility of a transfer of responsibility from the adolescent to the coordinator, which would be an undesirable outcome.

Implications for clinical practice: Incorporation of a transition coordinator is considered integral to a transitional care program. It is appreciated that the role of a transition coordinator is dependent on available funding; suggestions to aid with obtainment of funding at a local level include the development of a business case that cites the requirements for delivery of IBD transitional care such as that provided in the CCA IBD audit¹⁴ as well as reference of recommendations provided in this consensus guideline.

Statement 8

Transition programs should incorporate access or referral pathways to relevant allied health professionals including a psychologist, social worker, and dietitian.

Grade of evidence: D1

Agreement rating: Appropriate, necessary

The transfer of care extends beyond that of the gastroenterologist or IBD nurse, and often can involve other medical specialists. These may include those managing extraintestinal manifestations, sexual/reproductive health, or surgeons, as well as other members of the allied health team including dietitians, psychologists, and social workers. A systematic approach to transfer of the care of such aspects is important, and again benefits from the input of a transition care coordinator. It is recommended that the GP is included as an integral member of the supporting medical team through the transition period. The referral to adult care needs to be tailored according to the health service environment, for example private vs public care, as well as the availability of different professionals in locations. The timing of the need for allied health input also needs to be considered; for example, there may not be a need for such resources at the time of transfer, but they subsequently may become critical.

Patient access to information on the accessibility and options they have to different professionals appropriate to their care may be highly variable. In general, there will be greater options in the adult sphere of IBD care than in the pediatric space, but these choices may not be readily apparent to the patient.

Implications to clinical practice: The transition of multidisciplinary care is fundamental to the transitional process, and usually extends beyond solely the gastroenterologist role. It is important for transition services to provide verbal and written information to inform their patients about local (or more distant, if appropriate) allied health professionals and multidisciplinary teams.

Statement 9

A joint clinic between the pediatric and adult gastroenterologists during the transition process should be facilitated on at least 1 occasion.

Grade of evidence: C1

Agreement rating: Appropriate, necessary

There was very broad agreement of the importance of at least a single joint appointment between the pediatric and adult IBD teams during the transition process. This is supported by several studies and other guidelines.^{18,29,81-83} The exact structure, timing, and frequency of such joint clinics will vary depending on the pediatric and adult services for the patient and should also vary depending on patient factors. In general, the appointment should include the pediatric and adult gastroenterologists and respective IBD nurses (and/or transition coordinator). In addition, other members of the team, such as dietitians and/or IBD surgeons, should be present as appropriate, as discussed in statement 8. Some patients may also require a longer transition process, with more than 1 clinic appointment. This may include a follow-up appointment with the pediatric service after the official transfer of care. Nurse-led transition clinics may focus on building a relationship between the young adult and the nurse. This can help the young adult feel more comfortable and confident as they transition to adult care. The use of telemedicine tools is effective and can facilitate this process when face-to-face clinics are not feasible, especially given the geographic challenges of Australasia.⁷⁶

Implications for clinical practice: Inclusion of a joint transition clinic in the transitional model of care is beneficial; it can differ across centers, including the attendance of varying members of the care team as well as the modality in which it is delivered.

Statement 10

Written medical handover must accompany each patient and include disease history, prior medication exposures, and other relevant past medical and social history.

Grade of evidence: C1

Agreement rating: Appropriate, necessary

Medical record transfer is an integral process of IBD transition care and is often not done well.⁸⁴ Three suggested templates of referral content may be considered for use, 2 from other countries (Canada and Japan) that are generalizable to centers in Australasia,^{19,85} as well as one developed by the New South Wales Transition Committee (Supplementary

Table 2). It is noted that investigations from the time of diagnosis, as well as most recently, are considered important.

It is recommended that medical records provided during the transition period are also provided to the GP as well as the patient. There has been demonstration of the benefits (improvement in disease-specific knowledge) resulting from providing young adult patients with disease-related medication information.²² A medical handover, however, is separate to any transition process or checklist, in that it is explicitly related to the patient's medical history, treatment schedules, and possible plans.

Electronic medical records potentially make this process easier, although lack of compatibility between different provider software systems can render this challenging. Australasia benefits from a novel cloud-based clinical management system designed for IBD care (Crohn's Colitis Care) that can facilitate this process between centers (Supplementary Figure 1).⁸⁶ Consumer feedback on this process emphasized that such information should also be provided to the patient, facilitating shared decision making, and could be critical should the patient's IBD provider change.

Additional considerations when using pro forma checklists relate to providing appropriate information to ensure equity for all adolescents, in particular those from indigenous groups or migrant families. Such factors may be inclusion of which pronouns they prefer and their name pronunciation spelled phonetically. It should be highlighted whether any adolescent requires/prefers a translator to be present, and the adolescent's preferred method of contact (text/email/phone call) should be included. Finally, it should state whether adolescents in New Zealand would like to have a Māori Health Advisor present for their first adult gastroenterology appointment, and in Australia an Aboriginal and Torres Strait Islander Liaison Officer. Additional considerations should be included as and when necessary or requested.

Implications for clinical practice: Timely provision of relevant medical records to the accepting adult gastroenterology team is integral to the transition process; templates or electronic medical record transfer can be of assistance. Inclusion of the patient and GP in the distribution of information aids with knowledge and continuity of care.

Statement 11

The provision of age-appropriate communication, information, and resources is recommended.

Grade of evidence: D1

Agreement rating: Appropriate, necessary

Communication, in both the verbal and written form, needs to be age appropriate. Consideration of age appropriateness incorporates the modality of information delivery including the role of technology (whether information delivery is technology-mediated), the mode of delivery (written or spoken), and the readability of the content.⁸⁷ Adolescents may need support for specific disease-related topics, such as on how to communicate necessary information about their medications and adherence, recent investigations, and treatment concerns and preferences.⁸⁸ In addition, they may need resources on how to seek advice and information, how to ask for clarification of clinical matters that they are unsure about and about alternative options, and also how to discuss and clarify aspects of the implementation of care.⁸⁸

Information should be available in different languages and be culturally appropriate. It is important to recognize that the information being provided is predominantly for the adolescent and no longer is for the parent. It is also important to have discussions regarding the validity of the content being read, for example the use of validated resources as opposed to search webpages such as Google. There is also a need to consider how the communication approach may need to adapt across the transition process. Nurse-led transition group educational sessions would offer a supportive environment for adolescents and their families to learn about the transition process and ask questions. The group setting may also provide a sense of community and shared experiences, which could improve patient engagement and satisfaction with the clinic. They can help find appropriate health services, provide support to attend clinics and ensure that young people stay engaged in adult health services. Gray et al⁷⁴ reported on the STEP (Self-Management Transition Enhancement Program) intervention of 1 face-to-face group session and 4 individualized telehealth sessions with a transition coach.

Increasingly, patients will be seeking information online, and from social media platforms, with questionable utility and often little to no regulation of content. As an example, 81 unregulated (produced by laypeople or influencers, not healthcare or pharmaceutical companies) TikTok videos relating to Crohn's disease were assessed for educational and factual value.⁸⁹ Results showed that 26% of videos were considered educational and 80% factual, and the main topics discussed were lifestyle topics, with quality control deemed to be impractical due to interobserver reliability.⁸⁹ There is limited research on the best way to support patients in this area, but there has been some demonstration of the benefits of discussion of online information with nurse.⁹⁰ It is therefore important that patients are provided with skills on how to seek disease-related content online and with access to appropriate support groups.

Implications for clinical practice: Communication with the transitioning adolescent needs to be presented in an age-, culturally, and technologically appropriate format.

Statement 12

The discussion of age-appropriate psychosocial and lifestyle issues is recommended during the transition process.

Grade of evidence: D1

Agreement rating: Appropriate, necessary

There is a paucity of data on the best method for communicating between IBD patients of any age and their clinical team.⁹⁰ Nevertheless, there was a very high degree of consensus that issues including mental health, sexual health, drugs and alcohol, education and employment, and fertility should be raised during the transition process. Apart from general medical care, these issues often interact with IBD and its medical and/or surgical treatments.

Some of these issues may have been discussed at diagnosis, treatment initiation, or other times on a patient's journey, but these conversations may have occurred with a carer/parental focus or may have been forgotten. Transition is an opportunity to identify or re-discuss these issues with the patient themselves and provide them with the opportunity to have confidential discussions with their clinician or other appropriate member of the IBD multidisciplinary team. Indeed,

our consumer feedback from such patients confirmed the importance of this opportunity, and it was suggested that the gastroenterologist should raise these issues, although patients sometimes prefer to discuss lifestyle issues with other members of the team.

Implications for clinical practice: The development of a transition checklist ensures that opportunities are provided for age appropriate psychological and lifestyle issues to be discussed during the process. Patients should be informed regarding the resources available to them, such as through CCA⁹¹ and CCNZ,⁹² as well as broader community resources that can be shared with them.

Statement 13

Inpatient and outpatient care of adolescents in adult hospitals should occur in an age-appropriate environment.

Grade of evidence: C1

Agreement rating: Appropriate, uncertain necessity

Ideally, all hospital patients should be admitted to a ward that is suitable for both their disease (ie, expert gastroenterology and/or surgical ward) and age/developmentally appropriate as recommended in the Australian and UK IBD standards.^{14,93} It is recognized that this will not always be achievable, but certainly there should be an effort to ensure optimal care and patient experience for patients at their most vulnerable. Flexibility on admission criteria to adult and/or children's wards can improve the options for patients during the transition process. Ensuring that all staff (nursing, medical—including radiology, anesthetics, and allied health professionals) have expertise in caring for young people is important in providing satisfactory transition care.³¹

Implications for clinical practice: In the design of the delivery of local transitional care, there needs to be consideration of the location and method by which care is being provided, both in respect to inpatient and outpatient care.

Statement 14

The transition process generally needs to include communication regarding the transfer of clinical management to the patient from the carer.

Grade of evidence: D2

Agreement rating: Appropriate, necessary

In general, communication in a pediatric clinic is directed to parents or carers. In the majority of cases after transfer, communication regarding patient care is directed to the patient. Indeed, this is a legal requirement when the patient turns 18 years old and may be appropriate in younger patients depending on individual circumstances. In practice, many parents remain involved in the administrative process of their child's care, but it is beholden on IBD units (and hospitals) to ensure that the communication is directed appropriately. This is particularly important, and can be challenging, in complex psychosocial situations or when there are differences of opinion in the best management course.

This process can be difficult for some parents/carers, who may have been dealing with their child's IBD care for more than a decade. The process therefore needs to be dealt with transparently, and with sensitivity, with a clear explanation about how the process of, for example, clinic appointments and reminders, will work after transfer of care. AYAs have

expressed that 2-way communication regarding transfer of skills and care from their parent to the transitioning IBD patient to be one of the main facilitators for successful transition.⁹⁴ The use of goal setting strategies may facilitate structured communication and transfer of skills.⁹⁵

When patients have issues with mental capacity, due to comorbidities or other reasons, the process needs to be adjusted. As with all the other components of the transition process, the best strategy for communicating with patients' needs to be individualized to their particular circumstances.

Implications for clinical practice: The style and method of communication will be dynamic during the transition period, ideally with a gradual shift from being parent/carer-based to patient focused. Issues around capacity and confidentiality have to be treated with sensitivity.

Discussion

This is the first guideline for transitioning care from pediatric to adult services for patients with IBD in Australia and New Zealand. A collaborative effort among a diverse group of experts, with substantial involvement from patients and stakeholders alongside feedback from indigenous groups, led to the development of this guideline. Using the RAM methodology,²¹ there was considerable agreement on recommendations early in the process. However, multiple rounds of decision making involving various stakeholders ensured the precise wording of each recommendation and comprehensive consideration of all aspects of the transition process. This methodology also facilitated the weighting of recommendations based on both appropriateness and necessity. Consumer involvement through Australian and New Zealand IBD patient advocacy groups ensured a balanced approach to the guidelines.

Crucially, this guideline strongly advocates for the implementation of a formalized transition process for patients with IBD (statement 1), where such a service is currently lacking for many patients.¹³ This support is crucial, as it has shown to improve patient outcomes.²² Additionally, guidance on transition readiness and self-management (statements 2 and 3) provides practical advice on addressing deficiencies in service provision, which has been linked to improved outcomes.^{52,96,97} Statements 5 and 6 emphasize the importance of timing and flexibility in the transition process, which has been highlighted in other guidelines,¹⁶⁻¹⁹ but are arguably even more important in the geographically diverse setting of Australasia. The recommendation for a transition coordinator (statement 7), supported by evidence,⁷⁸ underscores their critical role in service provision, despite being rarely available.¹³ Technical aspects of the transition process are addressed in the later statements (9-14). Recommendations cover various aspects, including the establishment of joint clinics (statement 9) and the mechanisms of information dissemination to healthcare professionals and patients (statements 10-12), acknowledging a rapidly changing landscape of technology for both the healthcare team (with electronic records) and patients (use of online information and communication tools). Statement 13 addresses the challenging issue of the physical environment for outpatient and patient care for adolescents with IBD. This is acknowledged as being difficult to achieve but should provide impetus for service improvement and, as always, flexibility. Finally, statement 14 addresses the sometimes

contentious issue of moving clinical communication from a family-centered to a patient-centered approach, with evidence showing this is critical in successful transition.⁹⁴

There have been other guidelines for IBD transition internationally,^{16,18,98} but Australia and New Zealand, as well as having different health systems, also have a much lower population density than the vast majority of countries. This, alongside other demographic features, creates an unusual circumstance for Australasian patients in particular for those who live outside major metropolitan centers. This highlighted the importance of individualizing the transition process, as mentioned in almost every recommendation.

There was widespread agreement on many of the statements in the first round of voting, and it was quickly acknowledged that the main drawbacks with such guidelines are feasibility and resource limitations. There was some discussion amongst the expert panel and stakeholders on the minimum acceptable standards for a transition service. However, given the vast geographic variation that this guideline covers and the emphasis on individual patient needs, we have not provided this, but rather have provided a necessity rating for each of the statements. While all statements still rated very highly on the necessity scale, a small number were deemed of uncertain necessity. This disparity in scoring may be expected in an area as geographically and resource diverse as Australasia and is a key reason that the steering committee ensured that representation for specialties came from many centers throughout Australia and New Zealand and that so many healthcare professional groups were included in the voting committee. While the major centers in both countries may be expected to be more richly resourced for IBD services, such as access to mental health support, transition coordinators, and age-appropriate environments for transitioning adolescents, this is not the case. Few hospitals in Australia have full multidisciplinary IBD teams available and many have significant resource and staffing limitations,¹⁴ with a similar picture seen in New Zealand.¹⁵ As such, the available multidisciplinary IBD team members may take on many roles within the transition process for adolescents, which may in turn bias their opinion of appropriateness or necessity of individual statements. A recent Australasian survey identified evidence of dual tasking, such as IBD nurse specialists also taking on the role of transition coordinator.¹³ As such, perceived need may be voted lower if a transition process is already in place that is seen to be effective. Voting scores were wide-ranging for the mental health statement (statement 4) for both appropriateness and necessity, but as was evident in the feedback from voting committee members, this was influenced by perception of what is desirable vs pragmatically possible.

Determining what is appropriate and necessary for the Australasian population of adolescents with IBD as a whole is inevitably going to produce diverse opinions. The benefit of collecting constructive and contextual feedback from the voting committee was in being able to establish reasons for any low scores, which often focused on resource limitations and did not relate to the perceived importance of the statement/resource.

Defining successful transition remains complex and subjective, but evidence suggests that structured transition programs improve outcomes for patients with IBD.⁹⁹ Regional-specific guidelines like this provide a framework for providers to improve their processes and advocate for appropriate care. The

availability of a guideline implementation checklist and the potential for pilot studies of translational research further support the adoption of these statements into practice. This guideline should provide evidence for IBD units and hospitals to advocate for greater resources to support their transition processes. The guidelines may provide greater clarity for the possibilities for roles to be shared between multidisciplinary team members, such as that of the transition coordinator. While advocating for resources to support an independent transition coordinator may not be feasible, these guidelines have shown that the role may be taken on by the IBD nurse, as is the preference of clinicians and already being practiced in a number of centers.¹³ A guideline implementation checklist has been made available to support adoption of these statements into practice (Supplementary Table 3), and the steering committee are well placed to implement pilot studies of translational research to assess feasibility of adopting the guidelines.

Conclusions

These guidelines serve as a vital resource for IBD units and hospitals, advocating for greater resources to support transition processes. They offer clarity on the roles of multidisciplinary team members and provide practical strategies for implementing transition programs, ultimately improving outcomes for patients at this critical life stage.

Supplementary data

Supplementary data is available at *Inflammatory Bowel Diseases* online.

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Conflicts of Interest

E.G. has received speaker fees from Takeda, Janssen, Nutricia, Aspen Nutritionals, AbbVie, Evolution Health, and H&H Group; and served on advisory boards for AbbVie and Janssen. A.J.W. has received honoraria from Ferring, Takeda, Janssen, Pfizer, Fresenius Kabi, Dr. Falk Pharma, Sandoz, and AbbVie; received grant support from Ferring and Dr. Falk Pharma; and served as a consultant for AbbVie and Dr. Falk Pharma. B.C. has received speaker fees from Celltrion, Dr. Falk Pharma, Ferring, Fresenius Kabi, Takeda, Janssen, AbbVie, and Sandoz;

and served on advisory boards for AbbVie, Janssen, Sandoz, Takeda, and Celltrion.

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