

ORIGINAL ARTICLE

# Transitional care of adolescents with inflammatory bowel disease to adult services varies widely across Australia and New Zealand

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## Key words

adolescents, colitis, crohn's disease, guidelines, IBD, transition.

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## Abstract

**Background and Aim:** Children and adolescents account for approximately 14% of inflammatory bowel disease (IBD) diagnoses. At an appropriate age and level of development adolescents with IBD have their care transferred from the pediatric to adult clinical team during a process termed “transition”. The study aim was to survey pediatric gastroenterologists throughout Australasia to identify commonality in the transition process to contribute to standardized guideline development.

**Methods:** A descriptive survey captured key variables: transition clinic format, process and infrastructure, transition assessments, and guidelines. The survey was distributed electronically to 59 Pediatric Gastroenterologists throughout Australasia in January 2023.

**Results:** Seventeen (29%) clinicians completed the survey: Australia 13 (76%), New Zealand 4 (24%). Thirteen (76%) respondents had access to a dedicated IBD transition clinic. Adolescents attended transition clinics 1–7 times, and the main processes transferred were: prescription provision, biologic appointments, and adult team contacts. Transition was first discussed age 13–15 years (53%), or 16–18 years (47%), with the main discussion topics including: continuing adherence (88%), smoking (59%), alcohol use (59%), recreational drug use (59%). Transition readiness assessments were done infrequently (24%). The minority (24%) used formal guidelines to inform the transition process, but 15 (88%) considered the development of a standardized Australasian guideline as beneficial/extremely beneficial.

**Conclusions:** This survey highlighted that transition care for adolescents with IBD is variable across Australasia. Australasian guideline development may optimize the transition process for adolescents with IBD and improve their longitudinal outcomes.

## Introduction

Inflammatory bowel disease (IBD) is a chronic immune-mediated condition of the gastrointestinal (GI) tract that can adversely affect a person's physical and psychosocial well-being. IBD diagnosed during childhood or adolescence accounts for between 1.5 and 14% of cases,<sup>1–3</sup> and children with IBD generally have a more extensive disease distribution than those diagnosed as an adult.<sup>4</sup> Children with IBD will eventually begin the process of transitioning from the family-centred care model of the pediatric clinical management team to the adult management team, with the final stage of the process being full transfer of care.<sup>5</sup> This generally happens between the ages of 16 to 18 years but is dependent on each adolescent's level of development and transition readiness, as well as country, system, and centre-specific

practices. The age at which transfer takes place differs between countries due to varying definitions of pediatric care, with the age in America determined to be an upper limit of 21 years, in Australia and New Zealand 18 years, and a substantial range in other countries.<sup>6</sup> The optimal age of transfer is best determined by the pediatric gastroenterologist in consultation with each adolescent and their family on an individual basis, and with involvement from the adult gastroenterologist where possible.

To meet the expectations of transfer, adolescents are expected to achieve self-management, have knowledge of their disease and own clinical history, and understand the need for continued adherence to their medication regimen and regular clinical assessments.<sup>5,7,8</sup> The transition process may be complex and requires an adolescent to master additional skills such as

communication, decision making and assertiveness.<sup>9,10</sup> However, since the transition process is generally not prioritized until the child reaches adolescence, the number of self-management skills to be acquired may be disproportionate to the given timeframe for developing the necessary expertise.<sup>11</sup> If adolescents haven't mastered the necessary self-management skills prior to transfer they may experience poor outcomes.<sup>11,12</sup> Adolescents with IBD around the world continue to experience adverse health outcomes after transfer due to low levels of treatment adherence and poor clinic attendance.<sup>12–15</sup> This finding is supported by feedback from adult gastroenterologists, with as few as 23% surveyed gastroenterologists considering adolescents with IBD adequately prepared for completing the transition process and transferring to the adult team.<sup>16</sup> Perceived and measured deficiencies have been reported in the areas of self-management skills, general IBD knowledge, knowledge of own clinical and treatment history, and independent functioning and management, which clinicians perceive as barriers to successfully completing the transition process.<sup>9,12,17,18</sup>

Implementation of specific transition guidelines and clinics has consistently been shown to improve outcomes for adolescents with IBD.<sup>19–21</sup> Structured guidelines may help facilitate the transition process for clinical teams caring for adolescents with IBD. Internationally, a small number of country specific recommendations have been developed by clinical experts based on experience and empirical evidence.<sup>22–26</sup> While such guidelines are available, there are no specific Australasian recommendations, and little is known of the level of concordance in Australasian clinical centres to local or international guidelines.

The objective of this study was to conduct an online survey among pediatric gastroenterologists across Australasia to assess the local standards of care for the transition process in all centres caring for adolescents with IBD. The aim of the survey was to identify commonality between centres, highlight deficiencies in the process when compared to international recommendations, and contribute to the development of Australasian specific IBD transition guidelines.

## Methods

**Study design and participants.** This study comprised the dissemination of a descriptive survey to delineate components of the transition process for adolescents with IBD currently occurring at individual centres throughout Australasia. Pediatric Gastroenterologists who are members of the Australasian Society of Pediatric Gastroenterology, Hepatology and Nutrition (AuSPGHAN) were invited to participate between January and February 2023. The study invitation and link to study documentation was distributed by email, with reminders sent after 2 weeks.

**Study outcomes.** Data were collected via electronic survey (Cognito forms, Columbia, South Carolina, US). Key variables centred on clinical experience and case-load, transition clinic format, transition process and infrastructure, clinical personnel involvement, transition assessments, and utilization of existing guidelines. Questions were also asked regarding the opinion of future standardized Australasian guidelines being developed,

components to be included, and additional factors that should be considered.

The survey content was developed by a multi-disciplinary team of adult and pediatric gastroenterologists, researchers, and transition specialists. The completed survey was reviewed and approved by the Executive members of the Pediatric Australasian Gastroenterology Research Network (PEDAGREE), who then distributed the survey to AuSPGHAN members.

**Ethics and consent.** All participants provided consent to take part in the survey study. The study was reviewed and approved by the University of Otago Human Ethics Committee (D22/340).

**Statistical analysis.** Descriptive analysis was the main format of analysis. Numbers and percentages were used to indicate between group differences. Analysis carried out using SPSS version 28.0.1, IBM Corp, Armonk, NY, US.

## Results

Fifty-nine AuSPGHAN members were invited to participate with 17 (29%) completing the survey (Table 1). Thirteen (76%) respondents were based in Australia and 4 (24%) in New Zealand (NZ). The mean duration of caring for children with IBD was 16 years (SD 11.7, range 2–40 years). The majority of respondents (88%) had an individual caseload of less than 150 children with IBD, and a shared caseload in their centre of more than 200 children (82%).

**Dedicated IBD transition clinics.** Thirteen (76%) respondents reported that the centre they worked in had a dedicated transition clinic to facilitate the transfer of adolescents from the pediatric to adult health care services. Three of these transition clinics were stated as being limited to the local regional

**Table 1** Region of practice and clinical encounter information for participating Australasian clinicians

Variable	Category	n (%)
New Zealand region	North Island	3 (18)
	South Island	1 (6)
Australia region	Queensland	2 (12)
	New South Wales	5 (29)
	Victoria	5 (29)
	South Australia	1 (6)
Attends satellite/outreach clinics	Yes	7 (41)
Healthcare system	Public	9 (53)
	Public + private	8 (47)
IBD outpatient clinics per month	<5	10 (59)
	6–10	4 (23)
	>10	3 (18)
Review of inpatients with IBD	Daily	3 (18)
	At least 1/week	3 (18)
	Less 1/week	8 (46)
	Varies	3 (18)
Multi-disciplinary IBD team	Yes	14 (82)

Numbers rounded up/down as appropriate.

hospital and did not include services for adolescents transitioning to the wider geographic area, with some centres transitioning adolescents to up to 15 other adult GI service centres with no transition clinic available. Ten respondents provided details of the clinical team involved, frequency of visits, and transfer process during the transition clinic (Fig. 1). When asked to rate the importance of a transition clinic for children with IBD, 16 (94%) of respondents rated it as beneficial /extremely beneficial.

Of the seven the clinicians who also attend satellite/ outreach IBD clinics only two have a dedicated transition clinic at the outreach centre. Of the eight clinicians who also see adolescents with IBD in private centres, five reported that the transition process follows the same format as in public practice.

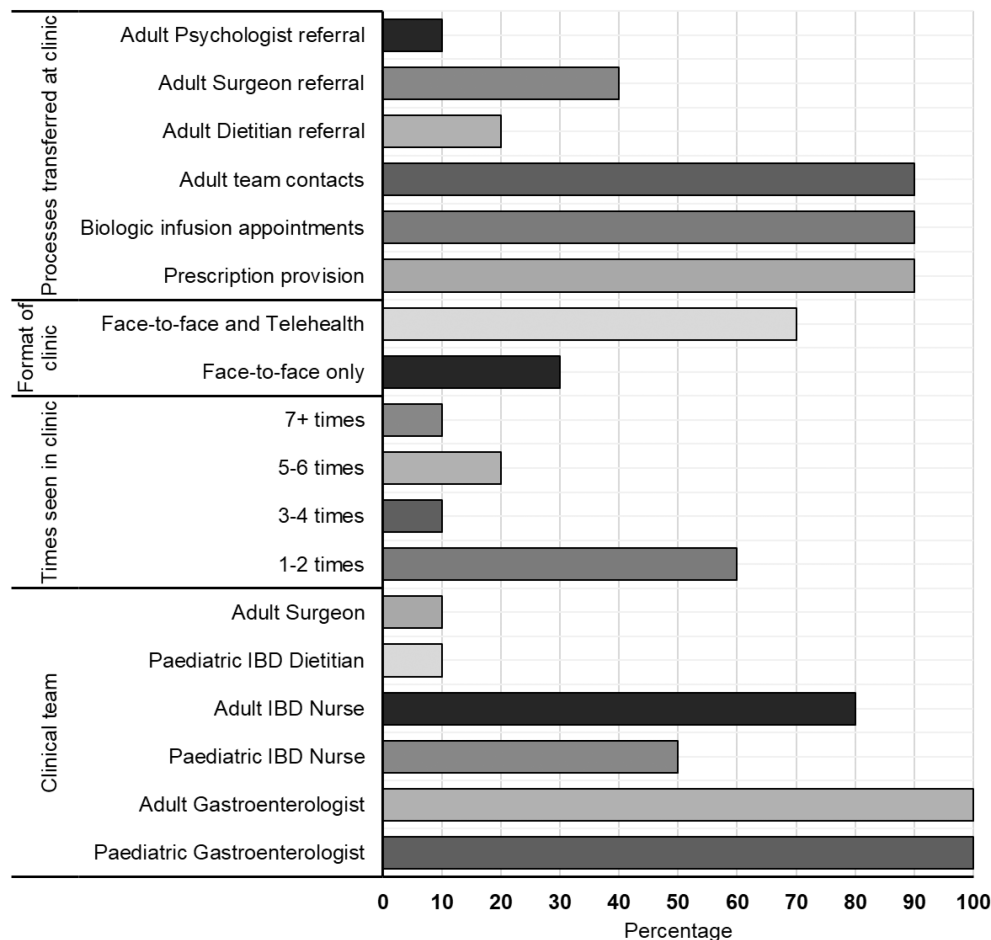
**Transition process.** Nine of the 17 respondents (53%) first discussed transition with children with IBD at the age of 13–15 years, and the remainder at age 16–18 years (47%). The topics discussed during the transition process were varied, with the importance of continued adherence being the most common (Fig. 2). Only eight (47%) of the study cohort provided education/support materials about the transition process to their patients. Of these, seven reported the use of booklets, three

recommend national support groups and websites and two conduct teaching sessions. One respondent stated that their centre has a specific specialist transition service for children with chronic health conditions where they can access support.

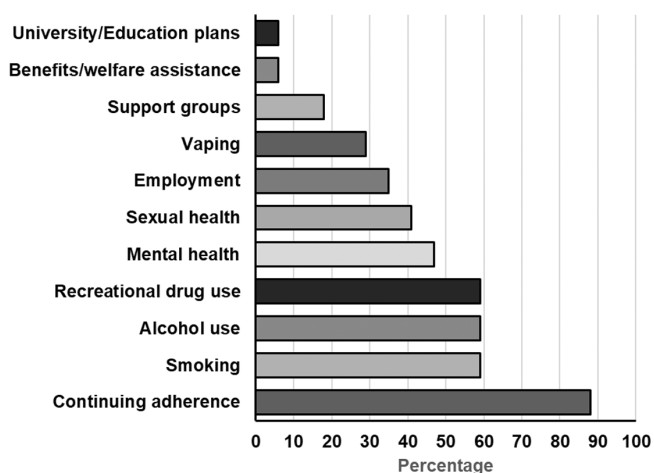
**Transition infrastructure.** Only seven (41%) of respondents reported that they have access to a transition support service their patients can engage with, all of which are based in the paediatric centre. Seven (41%) respondents identified a lead coordinator for the transition process at their centre: for four this is the paediatric IBD nurse, one is the adult IBD nurse, and two have a transition coordinator as a stand-alone role.

**Transition assessments.** Transition readiness assessments are carried out by just four respondents. The most common assessments were IBD knowledge (4/4), self-management skills (4/4), transition readiness (3/4), and one assessing each of the following: adherence, quality of life, own clinical IBD history, and anxiety/depression.

**GP involvement.** All but one respondent involved the adolescent’s GP in the transition process. The main form of



**Figure 1** Current IBD transition clinic components and processes (Data from 10 respondents).



**Figure 2** Topics currently discussed with adolescents with IBD transitioning to adult services.

involvement by 15 (82%) was to send a letter to the GP to inform them of initiation of the transition process. Discussions with the child/carer regarding the ongoing role of the GP were conducted by nine (53%), while eight (47%) sent a letter to the GP informing them of completion of the transition process, and one (6%) sent the GP a summary letter.

**Transition guidelines used in centres.** The majority (76%) of the respondents did not use any local, national, or international guidelines to inform their transition practice. One (6%) respondent reported that transition guidelines specific to children with IBD were available in their centre. Three (18%) respondents reported using two specific international chronic/GI disease transition guidelines to inform their transition process,<sup>27,28</sup> neither of which are IBD specific.

### Standardized Australasian guidelines

**Opinion.** When asked to rate their opinion of having standardized Australasian guidelines to inform the transition of adolescents with IBD, 15 (88%) of participants rated it as likely to be beneficial/extremely beneficial, while two (12%) were neutral.

**Components.** When asked what should be included in a standardized Australasian transition guideline a number of components were well supported. For example, 11/17 (65%) endorsed the inclusion of transition assessments, and there was a preference towards starting the transition process at the age of 13–15 years (Fig. 3). Additional comments were made regarding inclusion of a framework for assessing psychological state/needs, guidance around sexual health issues (including gender identity), and the incorporation of a virtual model to facilitate transition clinics at several different hospitals.

**Factors for consideration in standardized guidelines.** Additional factors were rated for their importance during the transition process: developmental level and child readiness were the most highly rated (Fig. 4).

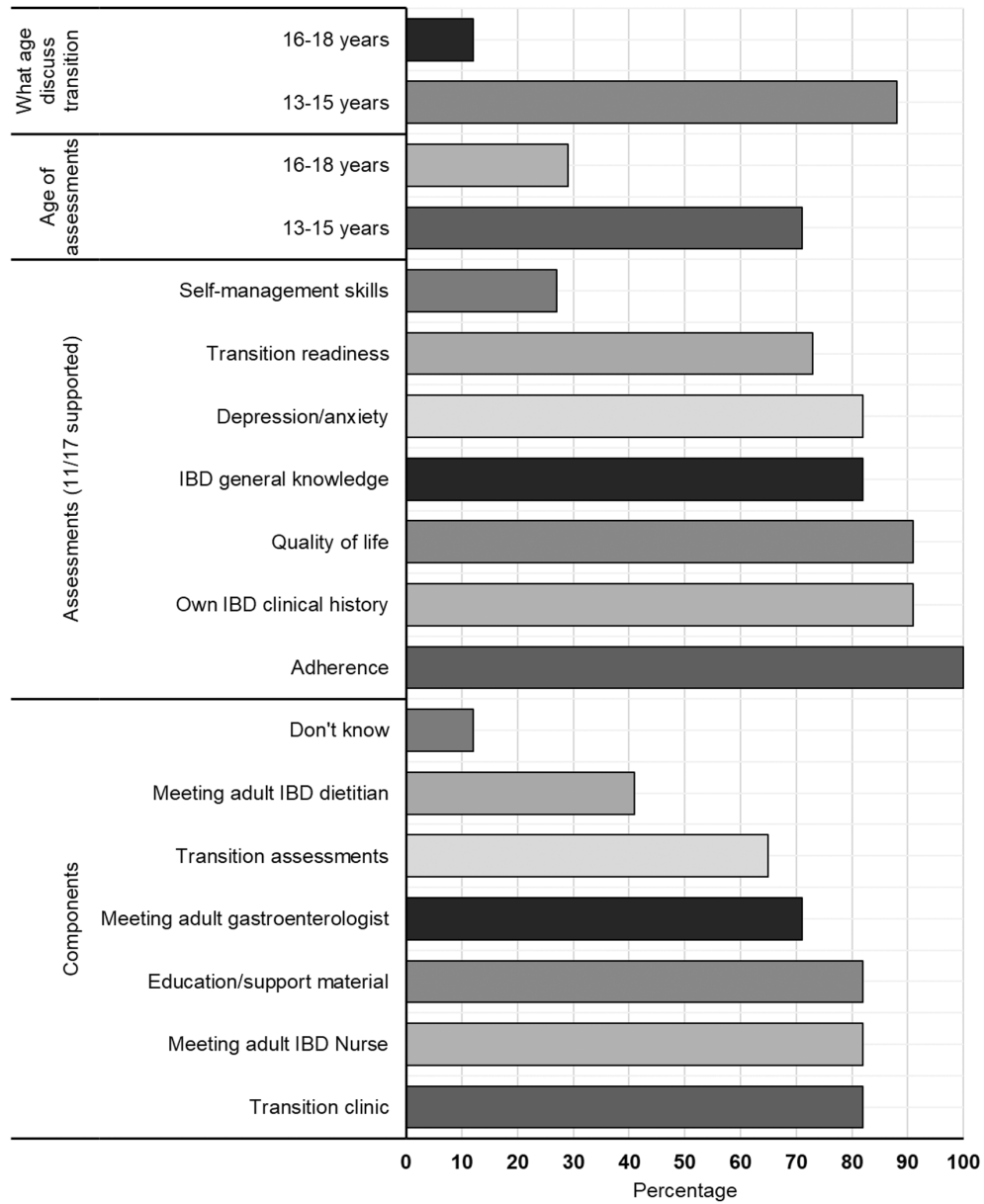
**Additional feedback.** All respondents provided free text feedback on what they considered barriers and facilitators to successful transition of adolescents with IBD. The main themes that emerged were common as both facilitators and barriers to effective transition for adolescents with IBD, relating to having Allied Health team members, as well as resources and time (Table 2).

## Discussion

This survey study identified that there was no standardized approach to the transition of adolescents with IBD from pediatric to adult care across Australasia. While many survey respondents reported that they had a dedicated transition clinic to facilitate the process, there was little consistency in the infrastructure of the clinics or wider transition infrastructure. Few clinicians utilized guidelines to inform the transition of their adolescent patients. There was strong agreement on the components that should be included in the process of standardized Australasian guideline development, despite these practices currently being carried out by few clinicians.

The finding that the majority (93%) of respondents used no IBD specific guidelines to inform their practice in transitioning adolescents with IBD to adult care warrants considerable attention. This is a surprising finding and highlights a lack of progress as a national IBD audit carried out in Australia in 2012–2013 (Crohns and Colitis Australia [CCA] audit 2016) revealed that few hospitals had IBD protocols of any type available for clinicians.<sup>29</sup> While recommendations had been made for improvement in the delivery of IBD care, including many aspects of transition, it appears as if considerable deficits remain. Furthermore, a number of international IBD guidelines are available to help inform the transition process.<sup>22–26</sup> However, these guidelines have been developed in other countries and may not account for differences in health care infrastructure, and geographic dispersion of patients and treatment centres. One of the reported barriers to effective transition among clinicians in the current study was the geographic limitations for adolescents to attend transition clinics, a consideration that may not be accounted for in guidelines in other countries. In other research studying adherence to IBD guidelines in Australia, the applicability of international IBD guidelines has been reported as a limitation to adherence due to differences in, for example, prescribing practices.<sup>30,31</sup> Clinician adherence to nationally developed Australian or New Zealand IBD specific clinical guidelines has been reported at levels of approximately 70%,<sup>32,33</sup> and confidence in Australian IBD guidelines high at 92%.<sup>34</sup> In combination with the finding in the current study that 88% of respondents supported the development of standardized Australasian IBD transition guidelines, undertaking this process would likely be well received.

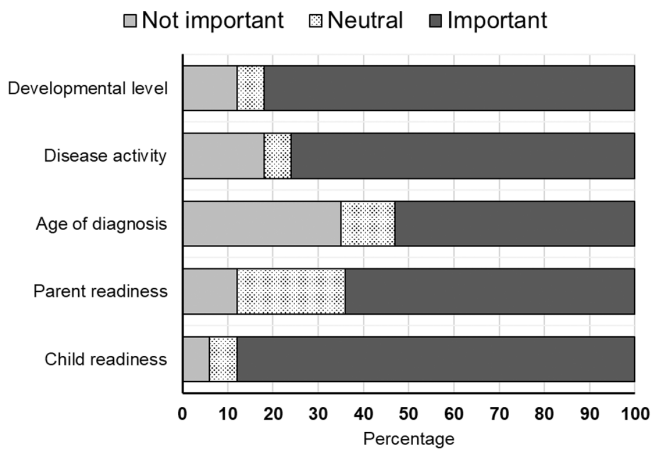
There is an apparent disconnect between respondent answers of current transition practices in the survey, and those factors considered important for inclusion in standardized Australasian guidelines. As examples, only 4 (24%) clinicians carry out transition readiness assessments in current practice, but 11 (65%) endorsed inclusion of such assessments in a standardized guideline. In addition, 53% currently start the transition process at age 13–15 years, but 88% endorsed this age to be recommended in standardized guidelines. Further, less than half



**Figure 3** Supported components of a standardized Australasian transition guideline for adolescents with IBD.

**Table 2** Factors considered by respondents as facilitators and barriers to successful transition for adolescents with IBD

Facilitators	n (%)	Barriers	n (%)
Allied Health involvement/MDT	8 (47)	Lack of Allied Health involvement/MDT	8 (47)
Motivated team	3 (18)	Lack of interested adult gastroenterologists	5 (29)
Resources/time/funding	7 (41)	Lack of resources/time	15 (88)
Empathy/support for adolescents	3 (18)	Poor patient engagement	3 (18)
Formal process/transition clinic	4 (24)	No standardized approach between centres	2 (12)
Communication +/-or coordination	4 (24)	Organization +/-or coordination to set up	4 (24)
Access to adult centres with IBD service	2 (12)	Geographic limitations for patients	4 (24)



**Figure 4** Factors considered important to consider during the transition, rated according to perceived importance.

currently provide educational materials to their patients during adolescence, but more than 80% endorse this to be incorporated into guidelines. All pediatric gastroenterologists in the current study providing information on dedicated transition clinics reported that the adult gastroenterologists were included in that setting. However, only 70% of the cohort overall reported that the adult gastroenterologist should be recommended as part of the clinical team component in Australasian guidelines if developed. The importance of adult gastroenterologist and MDT involvement should not be underrated for providing continuation of care as part of a structured programme for the adolescent with IBD during the transition process and once they transfer. These simple disparities may indicate that while IBD transition guideline development may be beneficial, effective promotion and implementation would be a critical step to achieving clinical impact in the form of improved outcomes through their use for adolescents with IBD transitioning to adult care.<sup>35</sup> De-implementation of current practice and implementation of new practice standards may be difficult due to factors such as poor support in the workplace for guideline adherence, and a perception of there being no adverse outcomes from current practice.<sup>31,36</sup> However, both de-implementation and implementation of practice are known to be driven by outcome-expectancy, or the perceived net benefit to patients.<sup>31,36</sup> Standardized transition guidelines should, therefore, incorporate evidence-based recommendations of cost and patient benefit and be promoted through Australasian educational meetings and national society endorsement. Prioritization of known facilitators to IBD clinical guideline adherence and addressing barriers to adherence should be a focus of development and implementation. Such factors as relevance to country of work, brevity, cost, and ease of accessibility should be considered if novel Australasian guidelines were to be developed.<sup>30,31</sup>

One factor reported by many respondents in the survey as barriers and facilitators to effective transition care was not having or having allied health professional support respectively, in particular IBD Nurses. Interestingly, multi-disciplinary team (MDT) support with a particular focus on IBD nurses is also shown to

facilitate adherence to IBD guidelines.<sup>31,37</sup> In the previously discussed audit (CCA IBD audit 2016), 1% of centres caring for people with IBD had a full MDT available, and approximately 31% had an IBD Nurse that had ongoing secure funding.<sup>29,38,39</sup> The benefits of the MDT to the care of children, adolescents, and adults with IBD are known to be multifactorial. MDT care is preferred by patients and represents a key pillar in the holistic assessment and management of the biopsychosocial consequences that manifest as a result of the condition.<sup>40–42</sup> However, resource limitations are widespread throughout Australasian health care systems and represent a significant barrier to providing optimal care to adolescents with IBD both in terms of MDT accessibility as well as providing effective transition care, as stated by 88% of survey respondents in the current study.

**Strengths.** The broad range of time respondents had been caring for adolescents with IBD, as well as the variation in clinical encounter frequency and distribution throughout major centres, indicates that the current survey included a representative sample of pediatric gastroenterologists that would report on factors pertinent to those with more, and less, experience.

**Limitations.** The finding that 76% of respondents in this current study, less than 25% of those originally invited to participate, had dedicated IBD transition clinics in their centre indicates a degree of response bias towards clinicians completing the survey if they had transition processes in place. In comparison, a previous organizational audit carried out in Australia reported that only 24% of centres had an IBD transition clinic available.<sup>29</sup> Survey completion by additional respondents may have provided a more balanced opinion to survey questions and allowed for more in depth analysis of response patterns. The generalisability of the results of this study to other countries is limited by the variation in upper limits for pediatric care around the world. In Australasia the upper limit for pediatric care is 18 years of age, which provides a pre-determined cut-off for age of transfer. However, collecting data on the usual age of transfer would have been beneficial for comparison with other health care systems.

**Conclusion.** The results of this survey highlight that the delivery of transition care for adolescents with IBD is variable across Australasia, and that current practices do not necessarily align with those sought in a standardized guideline. Addressing these disparities with the development and implementation of guidelines for all centres in a region such as Australasia may contribute to the transition process being optimized for all adolescents with IBD. Standardized guidelines may also be used as a proxy measurement of service delivery that could be used to improve the quality of care across the whole region, thereby improving outcomes for this population by identifying where additional input and resources would be beneficial.

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## Ethics statement

The study was reviewed and approved by the University of Otago Human Ethics Committee (D22/340).

**Data availability statement.** All reasonable requests for original data should be directed to the corresponding author.

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