



Deposited via The University of Sheffield.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/id/eprint/175251/>

Version: Accepted Version

---

**Article:**

Johnson, L.E., Lee, M.J., Turner-Moore, T. et al. (2021) Systematic review of factors affecting transition readiness skills in patients with inflammatory bowel disease. *Journal of Crohn's and Colitis*, 15 (6). pp. 1049-1059. ISSN: 1873-9946

<https://doi.org/10.1093/ecco-jcc/jjaa245>

---

This is a pre-copyedited, author-produced version of an article accepted for publication in *Journal of Crohn's and Colitis* following peer review. The version of record Lara E Johnson, Matthew J Lee, Tamara Turner-Moore, Lydia R Grinsted Tate, Alenka J Brooks, Rachel S Tattersall, Georgina L Jones, Alan J Lobo, Systematic Review of Factors Affecting Transition Readiness Skills in Patients with Inflammatory Bowel Disease, *Journal of Crohn's and Colitis*, 2020, jjaa245 is available online at: <https://doi.org/10.1093/ecco-jcc/jjaa245>.

**Reuse**

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

**Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing [eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk) including the URL of the record and the reason for the withdrawal request.

1 **Title page**

2 **Systematic review of factors affecting transition readiness skills in patients with**

3 **inflammatory bowel disease**

4

5 **Authors**

6 Lara E. Johnson<sup>1</sup>, Matthew J. Lee<sup>2,3</sup>, Tamara Turner-Moore<sup>4</sup>, Lydia R. Grinsted Tate<sup>1</sup>, Alenka

7 J. Brooks<sup>5</sup>, Rachel S. Tattersall<sup>6</sup>, Georgina L. Jones<sup>4</sup>, Alan J. Lobo<sup>5</sup>

8

9 **Affiliations**

10 <sup>1</sup>University of Sheffield, Medical School, Sheffield, UK, <sup>2</sup>Department of Oncology and

11 Metabolism, University of Sheffield Medical School, Sheffield, UK, <sup>3</sup>Academic Directorate of

12 General Surgery, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK,

13 <sup>4</sup>Department of Psychology, School of Social Sciences, Leeds Beckett University, Leeds, UK,

14 <sup>5</sup>Academic Department of Gastroenterology, University of Sheffield and Sheffield Teaching

15 Hospitals NHS Foundation Trust, Sheffield, UK, <sup>6</sup>Department of Rheumatology, Sheffield

16 Teaching Hospitals NHS Foundation Trust and Sheffield Children's Hospitals, Sheffield, UK

17

18 **Corresponding author details**

19 L.E. Johnson, Email: [Ljohnson13@sheffield.ac.uk](mailto:Ljohnson13@sheffield.ac.uk), Address: The Medical School, University of

20 Sheffield, Beech Hill Road, Sheffield S10 2RX, Telephone: 0114 222 5522, Fax: 0114 222

21 4042

22

23 **Word count**

24 **3784**

1 **Study type**

2 Systematic review

3

4 **Conflicts of interest**

5 None: LEJ, MJL, GLK, TTM, LRGT, AJB

6 RST has received speaker fees from Janssen, AbbVie and Pfizer

7 AJL has acted as an advisory board member, consultant or speaker for Janssen, Takeda,

8 Vifor Pharma, Shield therapeutics, Abbott and MSD.

9

10 **Conference presentation**

11 1) Poster presentation 15<sup>th</sup> Congress of ECCO – Inflammatory Bowel Diseases 2020  
12 February 12-15, 2020 in Vienna, Austria

13 2) Poster presentation Adolescent Health Conference: Working together to bridge the  
14 gaps, Royal College of Practitioners: Original date 27/3/2020 [rescheduled due to  
15 COVID-19]

16

17 **Authors' contributions**

18 Conception and design of the study: LEJ, MJL, GLJ, RST, AJL

19 Data collection and analysis: LEJ, MJL, LRGT, TTM, RST, GLJ, AJL

20 Preparation of manuscript and critical review: LEJ, MJL, LRGT, TTM, AJB, RST, GLJ, AJL

21

22 **Keywords**

23 Transition, adolescents, systematic review

24

1 **Funding**

2 No specific funding has been received for this systematic review.

3

4 **Data Availability Statement**

5 The data underlying this article are available in the article and in its online supplementary  
6 material.

7

8

9

## 1 **Abstract**

### 2 **Background and Aims**

3 The incidence of inflammatory bowel disease (IBD) diagnosed before adulthood is increasing  
4 worldwide. Transition from paediatric to adult healthcare requires certain skills. The aim of  
5 this study was to identify factors affecting these skills.

### 7 **Methods**

8 This review was registered on the PROSPERO database (CRD42019152272). Inclusion criteria:  
9 1) studies of factors affecting transition readiness skills in patients with IBD 2) written in  
10 English 3) published since 1999. MEDLINE, CINAHL and PsychINFO databases were searched  
11 between 1999-2019. Quality was assessed using the Joanna Briggs Institute critical appraisal  
12 tools.

### 14 **Results**

15 Searches identified 822 papers. Sixteen papers were included. Age was positively associated  
16 with skills including disease knowledge and performing self-management behaviours (14  
17 studies). Improvement often occurs at 18, however, skill deficiency may still remain.  
18 Increased self-efficacy (confidence) was associated with greater disease knowledge and  
19 performing self-management behaviours (3 studies). Self-efficacy was positively correlated  
20 with transition duration (2 studies) and health-related quality of life ( $r=0.57$ ,  $p<0.001$ ) (1  
21 study), negatively correlated with depression ( $r=-0.57$ ,  $p<0.001$ ) and anxiety ( $r=-0.23$ ,  $p=0.03$ )  
22 (1 study), and associated with higher education level (2 studies) and a family history of IBD (1  
23 study). Females had higher self-management scores (3 studies), and greater healthcare  
24 satisfaction was significantly associated with higher knowledge (1 study). Greater transition

1 communication improved knowledge, self-management, and overall transition readiness (2  
2 studies).

3

#### 4 Conclusions

5 Potentially modifiable factors have been identified that could be supported in the  
6 transitioning IBD population to improve transition readiness. Identification of those with non-  
7 modifiable characteristics associated with poor readiness may aid targeted support.

8

9

10

11

12

## 1 Introduction

2 Inflammatory bowel disease (IBD) predominantly describes ulcerative colitis (UC) and Crohn's  
3 disease (CD), with a small percentage of patients diagnosed with an unspecified subtype (IBD-  
4 unclassified (IBD-U)). IBD is characterised by a remitting and relapsing disease course that can  
5 vary significantly between patients<sup>1,2</sup>. The incidence of IBD diagnosed in childhood is  
6 increasing worldwide<sup>3</sup>. In comparison to those diagnosed as adults, patients presenting with  
7 IBD in childhood typically experience a more severe and extensive disease course<sup>4-6</sup>. This  
8 brings additional challenges including the potential for growth failure, pubertal delay<sup>7</sup>, and  
9 psychological morbidities, including depression<sup>7-9</sup>.

10

11 Transition from paediatric to adult healthcare is an essential part of disease management for  
12 those diagnosed in childhood. Paediatric services are typically more family-focused, with a  
13 higher level of parental involvement. This contrasts with adult services where independence  
14 and autonomy are encouraged<sup>9</sup>. The time at which healthcare transition occurs may be an  
15 unstable period, with concurrent changes in other areas of life including education and  
16 employment<sup>10</sup>. Patients transferring to adult IBD care are at risk of loss to follow-up, poor  
17 adherence to medication and clinic visits, and other adverse clinical outcomes<sup>5</sup>. The  
18 importance of good, structured transition care has therefore been emphasised<sup>11</sup>.

19

20 Transfer refers simply to the physical move of care between services, and is only part of  
21 transition which has been defined as '*a purposeful, planned process that addresses the  
22 medical, psychosocial and educational/vocational needs of adolescents and young adults with  
23 chronic ... conditions as they move from child-centred to adult orientated healthcare  
24 systems*<sup>12</sup>. This process requires the development of skills identified as necessary to engage

1 with adult healthcare. These include performance of the skills required to successfully  
2 manage a condition on an everyday basis, termed self-management behaviours<sup>10,11,13,14</sup>;  
3 medication and disease knowledge<sup>11,14</sup>, and health-literacy *'the extent to which individuals*  
4 *have the capacity to obtain, process and understand basic health information'*<sup>15</sup>. Self-efficacy  
5 has also been identified<sup>11</sup>, defined as a perceived confidence in the ability to perform  
6 behaviours required for independent management<sup>16</sup>. Surveys of adult gastroenterologists  
7 have expressed suboptimal levels of these skills in young people with IBD<sup>17</sup>.

8

9 The aim of this study was to review the literature to identify factors related to transition  
10 readiness skills.

11

12

13

## 1 **Methods**

2 This review was registered on the PROSPERO database (CRD42019152272), conducted with  
3 reference to the Cochrane Handbook<sup>18</sup>, and reported in line with Preferred Reporting Items  
4 for Systematic Reviews and Meta-Analyses (PRISMA) guidelines<sup>19</sup> using a predefined protocol.  
5 A copy of the PRISMA checklist is provided in online supplementary data.

## 6

### 7 **Eligibility criteria**

8 Studies considered for inclusion had to be published from the year 1999 onwards and be full-  
9 text peer reviewed journal articles reporting primary data. Studies were included if they  
10 explored factors associated with transition readiness skills, defined as competencies  
11 considered necessary when engaging in adult healthcare. This encompassed the  
12 measurement of disease and medication knowledge, self-management behaviours, health  
13 literacy, and self-efficacy. Studies needed to focus on patients who were either preparing to  
14 transition, were of the age of transitioning, or had transitioned. Papers were excluded if they  
15 reported on long-term conditions other than IBD or were not written in English.

16

### 17 **Information sources and search strategy**

18 The databases MEDLINE, CINAHL and PsychINFO were searched between 1<sup>st</sup> January 1999 to  
19 the 31<sup>st</sup> October 2019, during September and October 2019. Searches used no limits and  
20 combined free text and thesaurus terms. Key terms included “inflammatory bowel disease”,  
21 “Colitis, Ulcerative”, “Crohn Disease”, “IBD”, “Transition to Adult Care”, “transition”,  
22 “transitioning”, “transition readiness”, “transition skills”, “transition readiness skills”, “Self-  
23 efficacy”, and “Self-Management”. A secondary search of bibliographies from papers that  
24 were of known significance, including review articles, was also conducted. A manual search

1 for the full published text was undertaken if a conference abstract appeared to be relevant.

2 Duplicates were then removed.

3

#### 4 Study selection

5 Titles and abstracts were screened against the eligibility criteria (LEJ) with secondary review

6 and resolution of queries (TTM). Potentially appropriate texts were read in full to assess

7 suitability for inclusion, with justifications of rejection recorded (LEJ). This process underwent

8 secondary review (TTM).

9

#### 10 Data extraction

11 Data were extracted into pre-designed tables (LEJ) with secondary review (TTM). Extracted

12 data included year of publication, country of origin, study design, primary outcome,

13 secondary outcome(s), sample size with patient details, factors explored for association,

14 strength of association, statistical test used, secondary outcome results, and research setting.

15

#### 16 Quality assessment

17 Study quality was assessed using the Joanna Briggs Institute critical appraisal tools<sup>20</sup>.

18 Appraisal criteria includes inclusion and exclusion criteria; study subjects and setting;

19 identification of and strategies to address confounding factors; validity and reliability of

20 outcome measurement, and appropriate statistical analysis. Each study was assessed for

21 quality (LEJ) with secondary review (LRGT) and resolution of queries.

22

#### 23 Summary measures

1 Statistical methods and summary measures used in each study were recorded and presented  
2 with confidence intervals and tests of significance (p-values) where appropriate.

3

#### 4 Data synthesis

5 This review was prepared as a narrative synthesis of factors, identified as those associated  
6 with transition readiness skills. Factors were categorised into potentially modifiable and non-  
7 modifiable, then grouped by type of factor. This review defines modifiable factors as those  
8 that could potentially be amenable to intervention by a healthcare professional or the  
9 healthcare system. Factors such as education level could be viewed as modifiable in the wider  
10 context of a patient's life, however it is unlikely these could be impacted by possible strategies  
11 employed by healthcare professionals. Age was included as a modifiable factor as although  
12 this cannot be changed, the age at which transition occurs could be modified. This review set  
13 a reported alpha significance level of less than 0.05 with regards to determining the  
14 significance of potential factors.

15

16

## 1 **Results**

### 2 **Study selection**

3 Initial searches identified 863 papers. After removal of duplicates and secondary searches,  
4 822 were screened for inclusion. Twenty-six full texts were retrieved and reviewed against  
5 the eligibility criteria. 10 papers were then excluded for the following reasons: factors not  
6 assessed (n=3), patients were not part of the transition cohort (n=3), participants assessed  
7 did not have IBD (n=1), transition readiness acquisition not assessed (n=1), and the articles  
8 were a literature review (n=2). Therefore, sixteen papers were included in the full review. The  
9 PRISMA study selection flow chart is shown in Figure 1.

10

### 11 **Study characteristics**

12 The sixteen included studies were published between 2010 and 2019 and reported on 1762  
13 patients aged between 10 and 29. Studies were conducted primarily in the USA (n=12)<sup>21-32</sup>  
14 and outpatient clinics were the principal research setting (n=13)<sup>21-23,25,26,29-36</sup>. Fourteen of the  
15 studies were cross-sectional<sup>21-24,26-32,34-36</sup>, and two longitudinal<sup>25,33</sup>.

16

### 17 **Outcomes**

18 The included studies measured a number of different outcomes related to transition skills. A  
19 detailed summary of these measures is provided in the online supplementary data. Three  
20 papers assessed medication or disease knowledge<sup>29,30,35</sup> and four evaluated performance of  
21 self-management behaviours<sup>21,23,24,31</sup>. Three studies also assessed self-management in  
22 addition to either overall transition readiness<sup>22</sup> or knowledge<sup>25,26</sup>. One study examined  
23 knowledge and self-management alongside functional health-literacy, an assessment of  
24 comprehension and numeracy level<sup>27</sup>. Three studies assessed self-efficacy only<sup>32,33,36</sup> and one

1 paper also examined self-management<sup>28</sup>. One study evaluated knowledge, self-efficacy, and  
2 perception of medical care, which involves how patients' conceptualise their care and  
3 relationships with providers<sup>34</sup>.

4

#### 5 Quality assessment

6 Issues were noted around inadequate reporting of inclusion and exclusion criteria<sup>24,32-34</sup> and  
7 recruitment time period and study location<sup>21,22,26,27,30</sup>. Six studies did not use validated tools  
8 to measure outcomes<sup>26-29,31</sup>. Nine studies did not account for multiple testing<sup>26-28,31-34,36</sup>,  
9 eight of which also did not assess and correct for potentially confounding factors<sup>26-28,31-34,36</sup>.

10

#### 11 Factors

12 Factors were divided initially into potentially modifiable and non-modifiable. Modifiable  
13 factors were further categorised into provider-related and other, and non-modifiable into  
14 demographic and disease-related factors. Further details regarding the method of factor  
15 assessment and statistical results of individual papers are provided in online supplementary  
16 data.

17

18

## 1 **Potentially modifiable factors**

### 2 Provider-related factors

#### 3 ***Transition communication***

4 Three studies examined transition communication<sup>21,22,30</sup>. *Rosen et al.* found no association  
5 between having a conversation about transition with providers and self-management<sup>21</sup>.  
6 *Gumidyala et al.*(A) and (B) obtained information from parents and patients regarding the  
7 frequency and length of transition discussions. Young people who reported more frequent  
8 and longer transition discussions had higher self-management and overall transition  
9 readiness scores (communication uniquely explained 4.2% and 25.7% of the variance in self-  
10 management and overall readiness scores respectively). Parent reports were also associated  
11 with improved overall readiness (8.9%)<sup>22</sup>. In contrast, improved knowledge was only  
12 associated with parent reported communication (4.3% of variance,  $p=0.039$ )<sup>30</sup>.

13

#### 14 ***Transition duration***

15 Improved self-efficacy from longer transition duration was demonstrated in two studies<sup>33,36</sup>.  
16 *Yerushalmy-Feler et al.* defined duration from the first referral to a transition clinic to moving  
17 services. Significant positive correlations were found between duration and self-efficacy in  
18 three out of twelve domains (knowledge of IBD [ $r=0.44$ ,  $p=0.02$ ], medication use [ $r=0.57$ ,  
19  $p=0.002$ ], knowledge of transition [ $r=0.56$ ,  $p=0.002$ ])<sup>33</sup>. *Zijlstra et al.* recruited patients still  
20 attending a transition clinic and recorded the length of time since the first clinic visit. Duration  
21 was positively correlated with three different domains (skills for visits [ $r=0.29$ ,  $p=0.04$ ],  
22 behaviour at clinic [ $r=0.53$ ,  $p=0.001$ ], transfer readiness [ $r=0.22$ ,  $p=0.02$ ]). Clinician ( $r=0.45$ ,  
23  $p=0.001$ ) and parent ( $r=0.25$ ,  $p=0.03$ ) scores rating patient independency were also positively

1 correlated with duration, but not adolescent scores ( $r=0.23$ ,  $p=0.11$ ) - though this study did  
2 not assess patients when they had completed transition<sup>36</sup>.

3

#### 4 ***Healthcare satisfaction***

5 Patient healthcare satisfaction was associated with increased knowledge (satisfaction  
6 explained 8.9% of score variance,  $p=0.004$ )<sup>30</sup>.

7

#### 8 ***Care setting***

9 Self-management scores were not significantly different when comparing patients being  
10 managed in either paediatric or adult services ( $p=0.43$ )<sup>21</sup>.

11

#### 12 Other

#### 13 ***Age***

14 Fifteen studies examined the relationship between age and transition readiness skills. Six of  
15 these studies evaluated the association between age and knowledge<sup>26,27,29,30,34,35</sup>. One paper  
16 found no significant relationship ( $r=0.103$ ,  $p>0.05$ )<sup>34</sup> and another reported that in patients  
17 aged 14-18, younger participants were more likely to recall having undergone a small bowel  
18 X-ray (OR 0.59 [0.35-0.996],  $p=0.048$ )<sup>35</sup>. The remaining four studies however demonstrated  
19 that older age was associated with increased knowledge<sup>26,27,29,30</sup>. For every age increase of  
20 one year, the odds of correctly naming a current biologic therapy or the adverse effects of  
21 medication increased by 38% (OR 1.38,  $p<0.001$ ) and 13% (OR 1.13,  $p<0.001$ ) respectively<sup>29</sup>.  
22 Additionally, participants older than 18 scored significantly higher on measures of IBD  
23 knowledge. Comparisons between patients younger and older than 14 also showed  
24 significant differences in knowledge of past-medical history ( $p=0.01$ )<sup>27</sup>.

1 Seven studies assessed self-management<sup>21-24,27,28,31</sup>. In one study, no difference in ability to  
2 perform self-management behaviours was identified for patients aged 16-18<sup>28</sup>. In the  
3 remaining six papers, older age was significantly associated with improved self-  
4 management<sup>21-24,27,28,31</sup>. Participants older than 18 had significantly higher self-management  
5 scores than those younger than 18<sup>24,27</sup>. Other studies also demonstrated however that  
6 comparing participants aged 18 and above with even older patients still produced significant  
7 age differences. Participants older than 24 had significantly higher self-management scores  
8 in comparison to those aged between 18-20 (median 4.64 IQR 4.3-4.8 vs 3.97 IQR 3.4-4.4,  
9  $p<0.0001$ )<sup>21</sup> and in another study, only 7.3% of participants older than 18 met the study's pre-  
10 determined benchmark for adequate self-management scores<sup>23</sup>.

11

12 Assessing knowledge and self-management together, older age was again significantly  
13 associated with higher scores<sup>25,28</sup>. *Stollon et al.* found that approximately half of the assessed  
14 domains were not mastered until the age of 18 or above<sup>25</sup>. Parent ( $p<0.01$ ) and patient  
15 ( $p<0.001$ ) reported overall transition readiness also had significant positive relationships with  
16 age<sup>22</sup>. Evaluating functional health literacy, participants older than 18 again demonstrated  
17 higher scores ( $p=0.03$ )<sup>27</sup>. Perception of medical care was not correlated with age ( $r=-0.150$ ,  
18  $p>0.05$ )<sup>34</sup>.

19

20 Four studies assessed self-efficacy with relation to age<sup>28,32-34</sup>. Two studies found no  
21 relationship<sup>28,32</sup> and one, a significant positive relationship ( $r=0.367$ ,  $p<0.01$ )<sup>34</sup>. *Yerushalmy-*  
22 *Feler et al.* evaluated participants both before and after a transition clinic. Older age was  
23 positively correlated with coping with IBD after transition was complete ( $r=0.43$ ,  $p=0.004$ ).  
24 Evaluating the difference in scores between the two time points however, younger age was

1 associated with better improvement in the domains 'coping with IBD' ( $r=-0.44$ ,  $p=0.02$ ) and  
2 'knowledge of transition' ( $r=-0.38$ ,  $p=0.04$ )<sup>33</sup>. Unlike other outcomes, the effect of age on self-  
3 efficacy seems inconsistent and small.

4

### 5 ***Self-efficacy***

6 Four papers assessed whether self-efficacy influenced other transition readiness skills<sup>22-24,30</sup>.  
7 No difference was found in self-management scores when asking patients to rate their  
8 confidence in their ability to manage their disease<sup>23</sup>. The remaining three studies used  
9 validated self-efficacy measures. Greater self-efficacy was associated with both increased  
10 knowledge (self-efficacy explained 4.3% of score variance,  $p=0.039$ )<sup>30</sup> and self-management,  
11 explaining 16% of the variance in self-management scores in one study ( $p=0.001$ )<sup>24</sup> and 3.9%  
12 in another ( $p<0.05$ )<sup>22</sup>. Self-efficacy was also positively related to parent reported transition  
13 readiness (6.7%,  $p<0.05$ )<sup>22</sup>.

14

### 15 ***Autonomy granting***

16 *Gumidyala et al.(A)* assessed parent autonomy granting, the extent to which parents delegate  
17 appropriate levels of control and independent behaviour to their child<sup>37</sup>, and found no  
18 association with knowledge<sup>30</sup>.

19

### 20 ***Mental health***

21 Three studies examined the effects of mental health<sup>21,24,32</sup>. Resilience did not predict self-  
22 management<sup>24</sup>. No significant association was found between overall self-management  
23 scores and anxiety or depression. Depression however was associated with talking more  
24 openly with providers ( $r=0.29$ ,  $p=0.04$ )<sup>21</sup>. Contrastingly, depression ( $r=-0.57$ ,  $p<0.001$ ) and

1 anxiety ( $r=-0.23$ ,  $p=0.03$ ) were both related to lower self-efficacy scores. Self-esteem did not  
2 have an association with self-efficacy ( $r=0.23$ ,  $p=0.05$ )<sup>32</sup>.

3

#### 4 **Adherence**

5 *Rosen et al.* defined non-adherence as failure to either adhere to medication dosages or  
6 attend an appointment. Patients classified as 'non-adherent' did not have significantly  
7 different overall self-management scores, however did score significantly lower in the domain  
8 'managing medications' (median: 4.35 [IQR 3.3-4.8] vs 4.75 [IQR 4.3-5]  $p<0.01$ )<sup>21</sup>.

9

#### 10 **Non-modifiable factors**

##### 11 Demographic

##### 12 **Gender**

13 Twelve studies examined participant gender<sup>22-25,27,28,31-33,35,36</sup>. Three studies found that  
14 female participants had higher self-management scores<sup>22,23,31</sup> for example, they were more  
15 likely to order refills ( $p=0.017$ ) or prepare questions for appointments ( $p=0.009$ )<sup>31</sup>. *Zijlstra et*  
16 *al.* however found that male participants had higher median self-efficacy scores in three out  
17 of twelve domains<sup>36</sup>. *Benchimol et al.* also found that male participants were more likely to  
18 remember the correct date of their last admission (OR 6.82 [95% CI 1.75-26.6],  $p<0.01$ ) and  
19 colonoscopy (OR 2.83 [95% CI 1.03-7.80],  $p<0.05$ )<sup>35</sup>.

20

##### 21 **Socioeconomic status**

22 *Carlsen et al.* found no association between self-management and any socioeconomic  
23 indicators<sup>24</sup>. In another study however, those from higher socioeconomic groups had greater  
24 increases in knowledge and self-management scores over time ( $p=0.01$ ), though there was no

1 difference in baseline scores<sup>25</sup>. In contrast, *Huang et al.* reported that a higher percentage of  
2 participants from a lower socioeconomic group had a health literacy level classified as  
3 adequate for transition compared to those from a higher socioeconomic group (25% vs 6%,  
4  $p < 0.02$ )<sup>27</sup>.

5

### 6 ***Race / Ethnicity***

7 *Izaguirre et al.* found no association between race/ethnicity and self-efficacy<sup>32</sup>. Two other  
8 papers grouped participants into 'white' and 'other'. Those classified as 'white' had  
9 significantly higher knowledge and self-management scores at baseline ( $p = 0.01$ ), but not over  
10 time ( $p = 0.09$ )<sup>25</sup>. A higher percentage of 'white' participants also had a health literacy level  
11 classified as adequate for transition (18% vs 3%, white vs non-white; percentage ready to  
12 transition  $p = 0.03$ ). Higher scores for knowledge and functional health-literacy were also  
13 reported, however self-management was not influenced by race/ethnicity<sup>27</sup>.

14

### 15 ***Education level***

16 Education level did not influence self-management in one study<sup>21</sup>. Only one self-efficacy  
17 domain was significantly higher for those with a higher education level (knowledge of  
18 diagnostic tests, 90% vs 81% [high vs. low],  $p = 0.009$ )<sup>36</sup>. *Izaguirre et al.* found that those in  
19 middle school had lower self-efficacy scores than those in high school ( $p = 0.01$ ) and college  
20 ( $p = 0.007$ ), but not in graduate school or the workforce<sup>32</sup>.

21

22

## 1 Disease related

### 2 **Diagnosis**

3 Seven studies evaluated the influence of diagnosis<sup>24,28,31-33,35,36</sup>. Two studies demonstrated  
4 significant effects, with both reporting different findings<sup>35,36</sup>. Patients with IBD-U were more  
5 likely to be aware of their diagnosis (OR 17.2, 95% CI 2.81-105.4, p=0.009) and those with UC  
6 more likely to correctly recall whether they had undergone a small bowel X-Ray (OR 5.59, 95%  
7 CI 1.29-24.2, p=0.008)<sup>35</sup>. In another study however, participants with CD had higher self-  
8 efficacy scores for independent behaviour during clinics (p=0.04)<sup>36</sup>.

9

### 10 **Disease duration and age at diagnosis**

11 Eleven studies assessed disease duration<sup>22-24,26,28-33,35</sup> and two studies found conflicting  
12 results<sup>35,33</sup>. Duration was positively associated with correctly recalling undergoing a small  
13 bowel X-ray (OR 1.38 [95% CI 1.06-1.83] p<0.05)<sup>35</sup> and negatively associated with  
14 improvement in self-efficacy scores for coping with IBD after transition (r=-0.55, p=0.003)<sup>33</sup>.  
15 *Stollon et al.* found no association between age at diagnosis and either knowledge or self-  
16 management<sup>25</sup>. When *Carlsen et al.* evaluated just participants over the age of 18, older age  
17 at diagnosis was associated with lower self-management scores [F(1) 5.50; R<sup>2</sup>=0.10; p=0.02]<sup>24</sup>.

18

### 19 **Disease activity**

20 Six studies examined disease activity<sup>21-23,33</sup>. *Rosen et al.* also collected information concerning  
21 the number of emergency department visits and hospitalisations during a 6-month follow-up  
22 period and found no relationship with self-management<sup>21</sup>. An association was found between  
23 increased absence from school and lower self-management scores [F(1)4.26; R<sup>2</sup>=0.31;  
24 p=0.001]<sup>24</sup>. A significant positive correlation was also demonstrated between health-related

1 quality of life and self-efficacy (0.57,  $p < 0.001$ )<sup>32</sup>. The same study found no effect for presence  
2 of extraintestinal symptoms ( $p = 0.67$ ) or previous IBD related surgery ( $p = 0.33$ )<sup>32</sup>.

3

#### 4 ***Family history***

5 A family history of IBD was associated with significantly higher self-efficacy scores ( $p = 0.01$ )<sup>32</sup>.

6

#### 7 ***Medication type***

8 Medication type did not significantly influence self-efficacy<sup>33</sup>.

9

## 1 **Discussion**

2 This systematic review identified potentially modifiable and non-modifiable factors  
3 associated with transition readiness. These are important to consider in clinical encounters  
4 and service design. The identification of modifiable factors enables the development of  
5 interventions, and the recognition of non-modifiable factors should encourage clinicians to  
6 adapt care for individual patients to improve transition readiness.

7

8 Self-efficacy has been measured as both an outcome and a contributory factor for transition  
9 readiness in this review – reflecting existing literature<sup>24,36</sup>. Effect sizes were relatively small,  
10 however higher levels of self-efficacy did positively influence self-management and  
11 knowledge<sup>22,24,30</sup>. This may be due to assessment of similar measures, or alternatively,  
12 confidence may support the development of other skills; belief in one's ability has been  
13 associated with successful IBD transition<sup>11</sup>. Unlike other skills, self-efficacy did not have a  
14 strong relationship with age. Interventions that support confidence development may  
15 improve transition readiness regardless of age. In adults with Crohn's disease, an  
16 individualised behavioural programme which helped patients identify and reach personal  
17 goals significantly improved self-efficacy<sup>38</sup>. A meta-analysis of community-based education  
18 programmes for long-term conditions also demonstrated self-efficacy improvements<sup>39</sup>. The  
19 association between transition duration and self-efficacy<sup>33,36</sup> suggests that transition as a  
20 planned, gradual process may assist in building confidence<sup>40,41</sup>. A positive relationship with  
21 family history<sup>32</sup> also indicates the potential importance of familiarity with the medical  
22 environment or the easy availability of a peer or mentor.

23

1 Older age was consistently associated with improved transition readiness skills, confirming  
2 findings from other long-term conditions<sup>42</sup>. Studies with a wider age range were included in  
3 this review due to the current uncertainty surrounding the appropriate age for transition.  
4 Some insight has been provided to this, with significant improvements in knowledge, self-  
5 management, and health literacy seen at the age of 18. However, there remain inadequacies  
6 even in those older than 18. This may indicate the need for an older transition age, allowing  
7 for transition to occur at a “developmentally appropriate” time<sup>43</sup>, or for a more prolonged,  
8 individualised process. The prefrontal cortex - one of the final areas of the brain to mature in  
9 young adulthood - is key for executive functioning. This encompasses the use of certain  
10 cognitive skills regarded as necessary for engaging in adult healthcare<sup>10,11</sup>, including working  
11 memory, planning and organisation, problem-solving, and self-control<sup>10,44</sup>. Young person  
12 specific clinics may extend the timeline for which patients are expected to acquire these  
13 necessary competencies<sup>5</sup>. Adolescents with long-term conditions also reportedly desire  
14 feelings of ‘normality’<sup>45</sup>, which may be provided through regular contact with others  
15 undergoing similar experiences at young person specific clinics<sup>45,46</sup>. Peer programmes in  
16 young people with IBD can offer valuable support and facilitate the discussion of issues  
17 affecting patients<sup>47</sup>.

18

19 The positive relationship between skill acquisition and transition communication<sup>22,30</sup> supports  
20 literature stating that good, early communication in transition services is important<sup>41,48</sup>. A  
21 study assessing transfer readiness in adolescents with various long-term conditions found  
22 that participants who described increased discussion regarding future transfer felt more  
23 ready<sup>49</sup>. The slightly conflicting findings regarding the influence of both parent and patient  
24 reported transition communication suggests that there may be a process of readiness

1 preparation outside the clinical setting, related to behaviours in the family social unit. The  
2 one study assessing healthcare satisfaction found a significant relationship with knowledge<sup>30</sup>,  
3 potentially indicating a further avenue of research or intervention. Satisfaction has been  
4 associated with desirable outcomes including appointment adherence<sup>50</sup> and is reportedly  
5 higher when patients feel involved in their healthcare<sup>51</sup>. Nevertheless, parent-autonomy  
6 granting was not significant in this review. It was however only examined by one study<sup>30</sup>, and  
7 literature has identified parental over-involvement as a transition barrier and encourages  
8 patients to attend appointments alone<sup>52</sup>. More robust investigation is therefore necessary to  
9 understand the relationship between autonomy and transition readiness skills.

10

11 Female participants demonstrated a tendency for improved self-management<sup>22,23,31</sup>. Male  
12 patients elicited higher scores in some areas<sup>35,36</sup>, but the effect sizes were small and  
13 confidence intervals wide for one study<sup>36</sup>. This apparent self-management advantage for  
14 female patients may be important to consider, however these findings were not consistent,  
15 with more papers not reporting any significant effects for gender. Socioeconomic status and  
16 race/ethnicity were other identified factors, supported by literature demonstrating both the  
17 economic and ethnic disparities regarding transition readiness and other healthcare  
18 outcomes<sup>53-55</sup>. Within this review however, the included population was predominantly  
19 white. Studies also had discrepant findings, with increased readiness levels associated with  
20 both higher and lower socioeconomic status.

21

22 There are limitations to this review. Methods of assessing transition readiness are not  
23 consistent, making comparison of the primary outcome difficult. This variation arises as there  
24 is no consensus on the best measure, making it difficult to ascertain the true strength of

1 associations. This was reflected in the variable assessment of quality related to outcome  
2 measurement. This issue also meant that statistical meta-analysis and robust quantitative  
3 investigation could not occur. Future studies should seek to address these issues.

4

5 Factors, such as transition communication, were also variably defined. The evidence base for  
6 many factors also remains relatively small, with only a limited number of studies examining  
7 their effects. Individual measures, such as skill levels, may also not be accurate surrogate  
8 measures for successful transition, and longitudinal studies are needed to examine this  
9 relationship. Quality assessment found that studies were not of universally high quality, with  
10 relatively consistent failure to address potentially confounding factors. Studies also  
11 undertook univariate analyses, leaving them open to error when assessing relationships.  
12 Another source of potential bias is the self-reported element of outcomes, perhaps therefore  
13 not providing an objective measure. The majority of included studies were conducted in the  
14 US, thus potentially making it difficult to extrapolate results to other regions where different  
15 systems for transition and caring for young people with IBD may exist.

16

## 17 **Conclusions**

18 This study has identified potentially modifiable factors associated with improved transition  
19 readiness. These factors should undergo further rigorous and systematic evaluation to  
20 identify whether intervention can improve outcomes. Further research is necessary to obtain  
21 agreement on measures of transition readiness with longitudinal studies to demonstrate the  
22 impact of changes in the approach to individual patients and the service as a whole.

23

1 **Acknowledgements**

2

3

4

5

6

## 1 References

- 2 1. Lamb C, Kennedy N, Raine T, *et al.* British society of gastroenterology consensus  
3 guidelines on the management of inflammatory bowel disease in adults. .  
4 <https://www.bsg.org.uk/resource/bsg-consensus-guidelines-ibd-in-adults.html>  
5 Accessed 9 July, 2019.
- 6 2. Kamp KJ, Brittain K. Factors that influence treatment and non-treatment decision  
7 making among individuals with inflammatory bowel disease: An integrative review.  
8 *Patient-Patient Centered Outcomes Research* 2018;**11**:271-84.
- 9 3. Sýkora J, Pomahačová R, Kreslová M, *et al.* Current global trends in the incidence of  
10 pediatric-onset inflammatory bowel disease. *World journal of gastroenterology*  
11 2018;**24**:2741-63.
- 12 4. Duricova D, Burisch J, Jess T, Gower-Rousseau C, Lakatos PL. Age-related differences  
13 in presentation and course of inflammatory bowel disease: An update on the  
14 population-based literature. *Journal of Crohn's and Colitis* 2014;**8**:1351-61.
- 15 5. Goodhand J, Hedin CR, Croft NM, Lindsay JO. Adolescents with ibd: The importance  
16 of structured transition care. *Journal of Crohn's & colitis* 2011;**5**:509-19.
- 17 6. Van Limbergen J, Russell RK, Drummond HE, *et al.* Definition of phenotypic  
18 characteristics of childhood-onset inflammatory bowel disease. *Gastroenterology*  
19 2008;**135**:1114-22.
- 20 7. Gasparetto M, Guariso G. Highlights in ibd epidemiology and its natural history in the  
21 paediatric age. *Gastroenterology research & practice* 2013;**2013**:829040.
- 22 8. Rosen M, Dhawan A, Saeed S. inflammatory bowel disease in children and  
23 adolescents. *JAMA Pediatr* 2015;**169**:1053-60.

- 1 9. Afzali A, Wahbeh G. Transition of pediatric to adult care in inflammatory bowel  
2 disease: Is it as easy as 1, 2, 3. *World J Gastroenterol* 2017;**23**:3624-31.
- 3 10. Brooks AJ, Smith PJ, Cohen R, *et al.* Uk guideline on transition of adolescent and  
4 young persons with chronic digestive diseases from paediatric to adult care. *Gut*  
5 2017;**66**:988-1000.
- 6 11. de Silva PS, Fishman LN. Transition of the patient with ibd from pediatric to adult  
7 care-an assessment of current evidence. *Inflammatory Bowel Diseases*  
8 2014;**20**:1458-64.
- 9 12. Blum RW, Garell D, Hodgman CH, *et al.* Transition from child-centered to adult  
10 health-care systems for adolescents with chronic conditions - a position paper of the  
11 society for adolescent medicine. *Journal of Adolescent Health* 1993;**14**:570-6.
- 12 13. Conley S, Redeker N. A systematic review of self-management interventions for  
13 inflammatory bowel disease. *Journal of nursing scholarship : an official publication of*  
14 *Sigma Theta Tau International Honor Society of Nursing* 2016;**48**:118-27.
- 15 14. Abraham BP, Kahn SA. Transition of care in inflammatory bowel disease.  
16 *Gastroenterology & hepatology* 2014;**10**:633-40.
- 17 15. Tormey LK, Reich J, Chen YS, *et al.* Limited health literacy is associated with worse  
18 patient-reported outcomes in inflammatory bowel disease. *Inflammatory Bowel*  
19 *Diseases* 2019;**25**:204-12.
- 20 16. Keefer L, Kiebles JL, Taft TH. The role of self-efficacy in inflammatory bowel disease  
21 management: Preliminary validation of a disease-specific measure. *Inflammatory*  
22 *Bowel Diseases Vol* 2014;**17**:614-20.

- 1 17. Hait EJ, Barendse RM, Arnold JH, *et al.* Transition of adolescents with inflammatory  
2 bowel disease from pediatric to adult care: A survey of adult gastroenterologists. *J*  
3 *Pediatr Gastroenterol Nutr* 2009;**48(1)**:61-5.
- 4 18. Higgins JPT, Thomas J, Chandler J, *et al.* Cochrane handbook for systematic reviews  
5 of interventions version 6.0 (updated july 2019). Cochrane, 2019.
- 6 19. Moher D, Liberati A, Tetzlaff J, Altman DG. The prisma group (2009). Preferred  
7 reporting items for systematic reviews and meta-analyses: The prisma statement.  
8 *PLoS Med* 2009;**6(7)**: e1000097.
- 9 20. Moola S, Munn Z, Tufanaru C, *et al.* Chapter 7: Systematic reviews of etiology and  
10 risk. in: Aromataris e, munn z (editors). *joanna briggs institute reviewer's*  
11 *manual*. the joanna briggs institute, 2017.  
12 <https://reviewersmanual.joannabriggs.org/>.
- 13 21. Rosen D, Annunziato R, Colombel JF, Dubinsky M, Benkov K. Transition of  
14 inflammatory bowel disease care: Assessment of transition readiness factors and  
15 disease outcomes in a young adult population. *Inflammatory Bowel Diseases*  
16 2016;**22**:702-8.
- 17 22. Gumidyala AP, Greenley RN, Plevinsky JM, *et al.* Moving on: Transition readiness in  
18 adolescents and young adults with ibd. *Inflammatory Bowel Diseases* 2018;**24**:482-9.
- 19 23. Gray WN, Holbrook E, Morgan PJ, *et al.* Transition readiness skills acquisition in  
20 adolescents and young adults with inflammatory bowel disease: Findings from  
21 integrating assessment into clinical practice. *Inflammatory Bowel Diseases*  
22 2015;**21**:1125-31.

- 1 24. Carlsen K, Haddad N, Gordon J, *et al.* Self-efficacy and resilience are useful predictors  
2 of transition readiness scores in adolescents with inflammatory bowel diseases.  
3 *Inflammatory Bowel Diseases* 2017;**23**:341-6.
- 4 25. Stollon N, Zhong Y, Ferris M, *et al.* Chronological age when healthcare transition  
5 skills are mastered in adolescents/young adults with inflammatory bowel disease.  
6 *World Journal of Gastroenterology* 2017;**23**:3349-55.
- 7 26. Whitfield EP, Fredericks EM, Eder SJ, Shpeen BH, Adler J. Transition readiness in  
8 pediatric patients with inflammatory bowel disease: Patient survey of self-  
9 management skills. *Journal of Pediatric Gastroenterology and Nutrition* 2015;**60**:36-  
10 41.
- 11 27. Huang JS, Tobin A, Tompane T. Clinicians poorly assess health literacy-related  
12 readiness for transition to adult care in adolescents with inflammatory bowel  
13 disease. *Clinical Gastroenterology & Hepatology* 2012;**10**:626-32.
- 14 28. Fishman LN, Barendse RM, Hait E, Burdick C, Arnold J. Self-management of older  
15 adolescents with inflammatory bowel disease: A pilot study of behavior and  
16 knowledge as prelude to transition. *Clinical Pediatrics* 2010;**49**:1129-33.
- 17 29. Fishman L, Houtman D, Groningen J, Arnold J, Ziniel S. Medication knowledge: An  
18 initial step in self-management for youth with inflammatory bowel disease. *Journal*  
19 *of pediatric gastroenterology and nutrition* 2011;**53**:641.
- 20 30. Gumidyala AP, Plevinsky JM, Pouloupoulos N, *et al.* What teens do not know can hurt  
21 them: An assessment of disease knowledge in adolescents and young adults with  
22 ibd. *Inflammatory Bowel Diseases* 2017;**23**:89-96.

- 1 31. Van Groningen NJ, Ziniel NS, Arnold NJ, Fishman NL. When independent healthcare  
2 behaviors develop in adolescents with inflammatory bowel disease. *Inflammatory*  
3 *Bowel Diseases* 2012;**18**:2310-4.
- 4 32. Izaguirre MR, Taft T, Keefer L. Validation of a self-efficacy scale for adolescents and  
5 young adults with inflammatory bowel disease. *Journal of Pediatric Gastroenterology*  
6 *& Nutrition* 2017;**65**:546-50.
- 7 33. Yerushalmy-Feler A, Ron Y, Barnea E, *et al.* Adolescent transition clinic in  
8 inflammatory bowel disease: Quantitative assessment of self-efficacy skills.  
9 *European Journal of Gastroenterology & Hepatology* 2017;**29**:831-7.
- 10 34. Hammerman O, Bayatra A, Turner D, *et al.* Initial development and validation of a  
11 transition readiness scale for adolescents with inflammatory bowel disease.  
12 *Gastroenterology research and practice* 2019;**2019**:5062105-.
- 13 35. Benchimol IE, Walters DT, Kaufman DM, *et al.* Assessment of knowledge in  
14 adolescents with inflammatory bowel disease using a novel transition tool.  
15 *Inflammatory Bowel Diseases* 2011;**17**:1131-7.
- 16 36. Zijlstra M, De Bie C, Breij L, *et al.* Self-efficacy in adolescents with inflammatory  
17 bowel disease: A pilot study of the “ibd-yourself”, a disease-specific questionnaire.  
18 *Journal of Crohn's and Colitis* 2013;**7**:e375-e85.
- 19 37. Kunz JH, JH G. Parental psychological control and autonomy granting: Distinctions  
20 and associations with child and family functioning. *Parenting*;**13**:2:77-94.
- 21 38. Keefer L, Doerfler B, Artz C. Optimizing management of crohn’s disease within a  
22 project management framework: Results of a pilot study\$. *Inflammatory Bowel*  
23 *Diseases* 2012;**18**:254-60.

- 1 39. Brady TJ, Murphy L, O'Colmain BJ, *et al.* A meta-analysis of health status, health  
2 behaviors, and health care utilization outcomes of the chronic disease self-  
3 management program. *Preventing chronic disease* 2013;**10**:120112-.
- 4 40. Rigoli L, Caruso RA. Inflammatory bowel disease in pediatric and adolescent patients:  
5 A biomolecular and histopathological review. *World journal of gastroenterology*  
6 2014;**20**:10262-78.
- 7 41. Nagra A, McGinnity PM, Davis N, Salmon AP. Implementing transition: Ready steady  
8 go. *Archives of disease in childhood - Education & practice edition* 2015;**100**.
- 9 42. Porter JS, Graff JC, Lopez AD, JS H. Transition from pediatric to adult care in sickle cell  
10 disease: Perspectives on the family role. *J Pediatr Nurs* 2014;**29(2)**:158-67.
- 11 43. Menon T, Afzali A. Inflammatory bowel disease: A practical path to transitioning  
12 from pediatric to adult care. *American Journal of Gastroenterology* 2019;**114**:1432-  
13 40.
- 14 44. D Y-T. Emotional and cognitive changes during adolescence. *Curr Opin Neurobiol*  
15 2007;**17(2)**:251-7.
- 16 45. Jordan A, Joseph-Williams N, Edwards A, Holland-Hart D, Wood F. "i'd like to have  
17 more of a say because it's my body": Adolescents' perceptions around barriers and  
18 facilitators to shared decision-making. *Journal of Adolescent Health* 2019;**65**:633-42.
- 19 46. Lipstein EA, Dodds CM, Britto MT. Real life clinic visits do not match the ideals of  
20 shared decision making. *The Journal of Pediatrics* 2014;**165**:178-83.e1.
- 21 47. Mackner LM, Ruff JM, K V. Focus groups for developing a peer mentoring program to  
22 improve self-management in pediatric inflammatory bowel disease. *Journal of*  
23 *Paediatric Gastroenterology and Nutrition* 2014;**59(4)**:487-92.

- 1 48. Allan C, Tim R, Jeremy RP, *et al.* Facilitating the transition of young people with long-  
2 term conditions through health services from childhood to adulthood: The transition  
3 research programme. *Programme Grants for Applied Research* 2019;**7**.
- 4 49. van Staa A, van Der Stege HA, Jedeloo S, Moll HA, Hilberink SR. Readiness to transfer  
5 to adult care of adolescents with chronic conditions: Exploration of associated  
6 factors. *Journal of Adolescent Health* 2011;**48**:295-302.
- 7 50. Litt IF, WR C. Satisfaction with health care: A predictor of adolescents' appointment  
8 keeping. *Journal of Adolescent Health Care* 1984;**5(3)**:196-200.
- 9 51. Haarbauer-Krupa J, Alexander NM, Mee L, *et al.* Readiness for transition and health-  
10 care satisfaction in adolescents with complex medical conditions. *Child: care, health*  
11 *and development* 2019;**45**:463-71.
- 12 52. Huang JS, Gottschalk M, Pian M, *et al.* Transition to adult care: Systematic  
13 assessment of adolescents with chronic illnesses and their medical teams. *The*  
14 *Journal of Pediatrics* 2011;**159**:994-8.e2.
- 15 53. Javalkar K, Johnson M, Kshirsagar AV, *et al.* Ecological factors predict transition  
16 readiness/self-management in youth with chronic conditions. *Journal of Adolescent*  
17 *Health* 2016;**58**:40-6.
- 18 54. Lotstein DS, Kuo AA, Strickland B, Tait F. The transition to adult health care for youth  
19 with special health care needs: Do racial and ethnic disparities exist? *Pediatrics*  
20 2010;**126 suppl 3**:S129-S36.
- 21 55. Braveman PA, Cubbin C, Egerter S, Williams DR, Pamuk E. Socioeconomic disparities  
22 in health in the united states: What the patterns tell us. *American journal of public*  
23 *health* 2010;**100**:S186-S96.
- 24

1 **Figure legends**

2

3 **Figure 1.**

4 PRISMA flow chart (*n=number of studies*)

5

6 **Figure 2.**

7 Significant potentially modifiable factors affecting transition readiness skills identified in this  
8 systematic review

9

10 **Figure 3.**

11 Significant non-modifiable factors affecting transition readiness skills identified in this  
12 systematic review

13

14 **Figure 4.**

15 How to assess the gaps identified in the literature, related to future study design

16

17

18

1 **Tables**2 **Table 1.** Summary of included papers with study characteristics including age of patients

3 assessed, transition readiness skill(s) assessed and method of assessment

<b>Paper</b>	<b>Sample Size</b>	<b>Age of patients assessed</b>	<b>Transition readiness skill(s) assessed</b>	<b>Summary of method of skill assessment</b>
<b>Benchimol 2011</b>	n=78	Range: 14-18 Mean: 16.2±1.25	Medication and disease knowledge	Patient completed survey
<b>Fishman 2011</b>	n=294	Mean: 16.7±3.5	Medication and disease knowledge	Patient completed survey
<b>Gumidyala 2017</b>	n=75	Range: 16-20 Mean: 17.39±1.2	Medication and disease knowledge	Patient completed survey
<b>Carlsen 2017</b>	n=87	Range: 16-23 Median: 19 (IQR 17-20)	Performance of self-management behaviours	TRAQ (Transition Readiness Assessment Questionnaire)
<b>Gray 2015</b>	n=195	Range: 16-25 Mean: 18.08±1.86	Performance of self-management behaviours	TRAQ
<b>Rosen 2016</b>	n=95	Mean in adult setting: 23.5±2.2 Mean in paediatric setting: 20.5±1.6	Performance of self-management behaviours	TRAQ

<b>van Groningen 2012</b>	n=294	Range: 10-29 Mean: 16.2	Performance of self-management behaviours	Patient completed survey
<b>Gumidyala 2018</b>	n=75	Range: 16-20	Performance of self-management behaviours and overall transition readiness	Readiness to Transition Questionnaire (RTQ): 1. RTQ-Overall 2. RTA-AR (Adolescent responsibility) Completed by patient and parent
<b>Stollon 2017</b>	n=144	Range: 12-22 Mean: 15.9±2	Disease and medication knowledge and performance of self-management behaviours	TRxANSITION Scale
<b>Whitfield 2015</b>	n=67	<14: (n=12) 14-17: (n=37) 18+: (n=18)	Disease and medication knowledge and performance of self-management behaviours	Patient completed survey
<b>Huang 2012</b>	n=74	Range: 10-20 Mean: 15	Disease and medication knowledge, performance of self-management behaviours, functional health-literacy, and overall adequate rates for transition	Patient completed surveys and questionnaires

<b>Izaguirre 2017</b>	n=95	12-17: (n=42) (44.2%) 18-25: (n=51) (53.7%)	Self-efficacy	IBD-Self-Efficacy Scale for Adolescents (IBD- SES-A)
<b>Yerushalmy- Feler 2017</b>	n=36	Range: 17-27 Mean: 19±1.8	Self-efficacy	IBD-yourself
<b>Zijlstra 2013</b>	n=50	Median: 16.3 (IQR 15.4-17)	Self-efficacy	IBD-yourself
<b>Fishman 2010</b>	n=40	Range: 16-18 16: (n=17) 17: (n=17) 18: (n=6)	Performance of self- management behaviours and self-efficacy	Patient and parent completed survey
<b>Hammerman 2019</b>	n=63	Mean: 16.6±2.1	Disease and medication knowledge, self-efficacy, perception of medical care	Patient completed questionnaire

1 n (number of participants) IQR (Interquartile range)

1 **Table 2.** Included studies and factors assessed for association with transition readiness skills. Associations found are demonstrated.

2

Paper	Transition skill assessed	Modifiable									Non-modifiable									
		Provider-related				Other					Demographic				Disease-related					
		Trans. Comm.*	Trans. Dur.**	Healthcare satisfaction	Care setting	Age	Self-efficacy	Autonomy granting	Mental health	Adherence	Gender	SES <sup>+</sup>	Race / Ethnicity	Edu. Level <sup>++</sup>	Diag. <sup>‡</sup>	Dur. <sup>ε</sup>	Age at Diag. <sup>δ</sup>	Disease activity	Family history	Med. <sup>θ</sup>
Benchimol 2011	Knowledge					✓(-)					✓(M)			✓(IBD-U, UC)	✓(+)					
Fishman 2011	Knowledge					✓(+)					✓(x)				✓(x)					
Gumidyala 2017	Knowledge	✓(+)		✓(+)		✓(+)	✓(+)	✓(x)							✓(x)					
Carlsen 2017	Self-management					✓(+)	✓(+)		✓(x)		✓(x)	✓(x)		✓(x)	✓(x)	✓(-)	✓(-)			
Gray 2015	Self-management					✓(+)	✓(x)				✓(F)				✓(x)		✓(x)			
Rosen 2016	Self-management	✓(x)			✓(x)	✓(+)			✓(-)	✓(+)			✓(x)				✓(x)			
van Groningen 2012	Self-management					✓(+)					✓(F)			✓(x)	✓(x)					
Gumidyala 2018	Self-management, overall transition readiness	✓(+)				✓(+)	✓(+)				✓(F)				✓(x)		✓(x)			

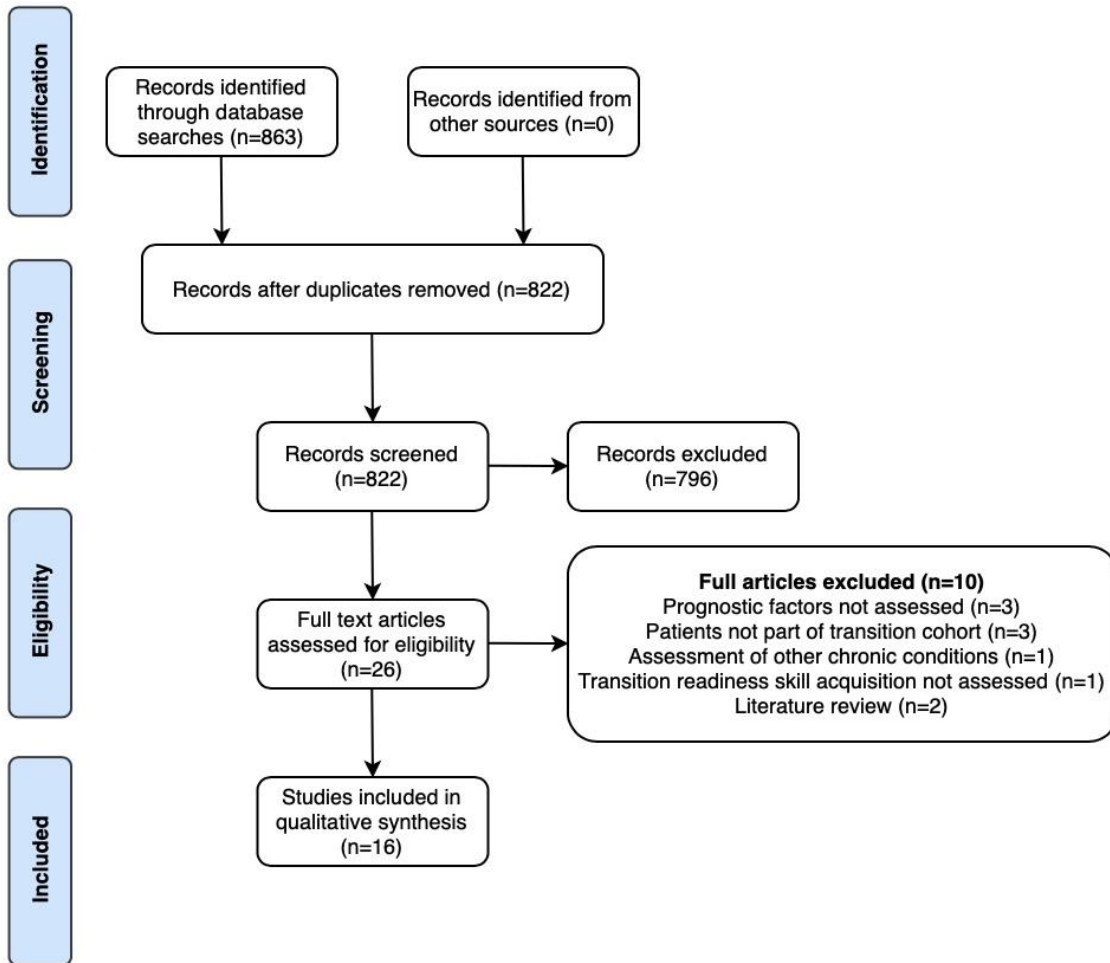
Stollon 2017	Self-management, knowledge					✓(+)					✓(x)	✓(+)	✓(w)				✓(x)		
Whitfield 2015	Self-management, knowledge					✓(+)											✓(x)		
Huang 2012	Self-management, knowledge, health-literacy					✓(+)					✓(x)	✓(-)	✓(w)						
Izaguirre 2017	Self-efficacy					✓(x)			✓(+)		✓(x)		✓(x)	✓(+)	✓(x)	✓(x)		✓(-)	✓(+)
Yerushalmy-Feler 2017	Self-efficacy		✓(+)			✓(+/-)					✓(x)				✓(x)	✓(-)		✓(x)	✓(x)
Zijlstra 2013	Self-efficacy		✓(+)								✓(M)			✓(+)	✓(CD)				
Fishman 2010	Self-management, self-efficacy					✓(x)					✓(x)				✓(x)	✓(x)			
Hammerman 2019	Self-efficacy, knowledge, perception of care					✓(+)													

1 \*Transition communication \*\*Transition duration +Socioeconomic status \*\*Education level ±Diagnosis εDisease duration δAge at diagnosis θMedication type (+) Positive association found (-)

2 Negative association found (x) No association found (M) Male gender (F) Female gender (w) 'white' race/ethnicity

1 **Figures**

2

3 **Figure 1.**

4

5

6

7

8

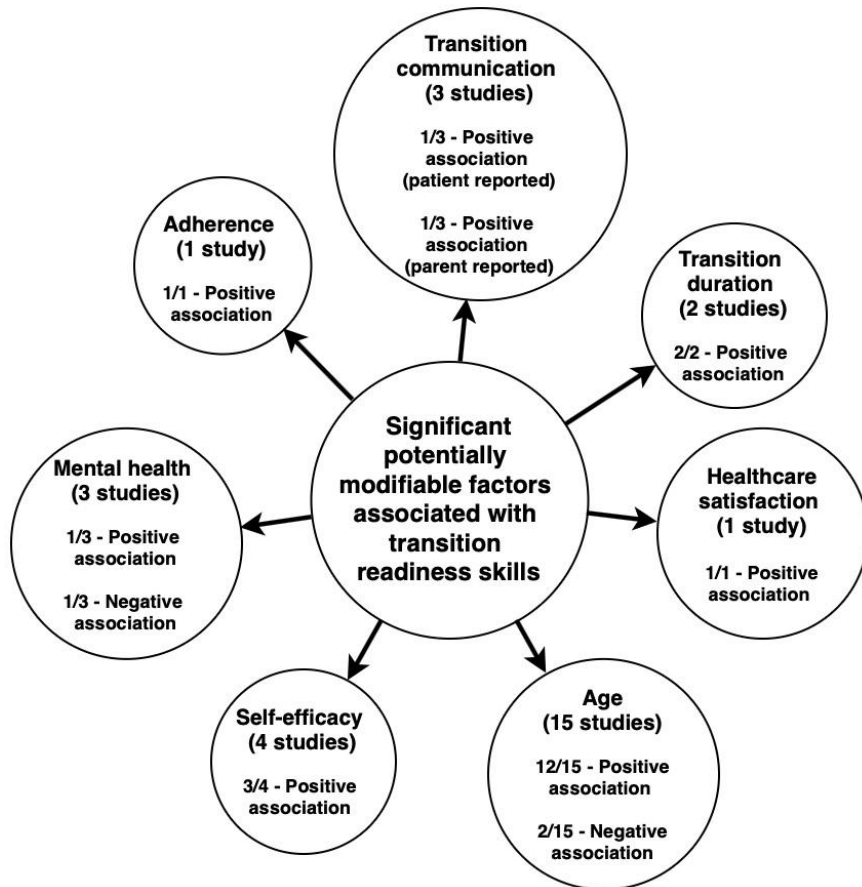
9

10

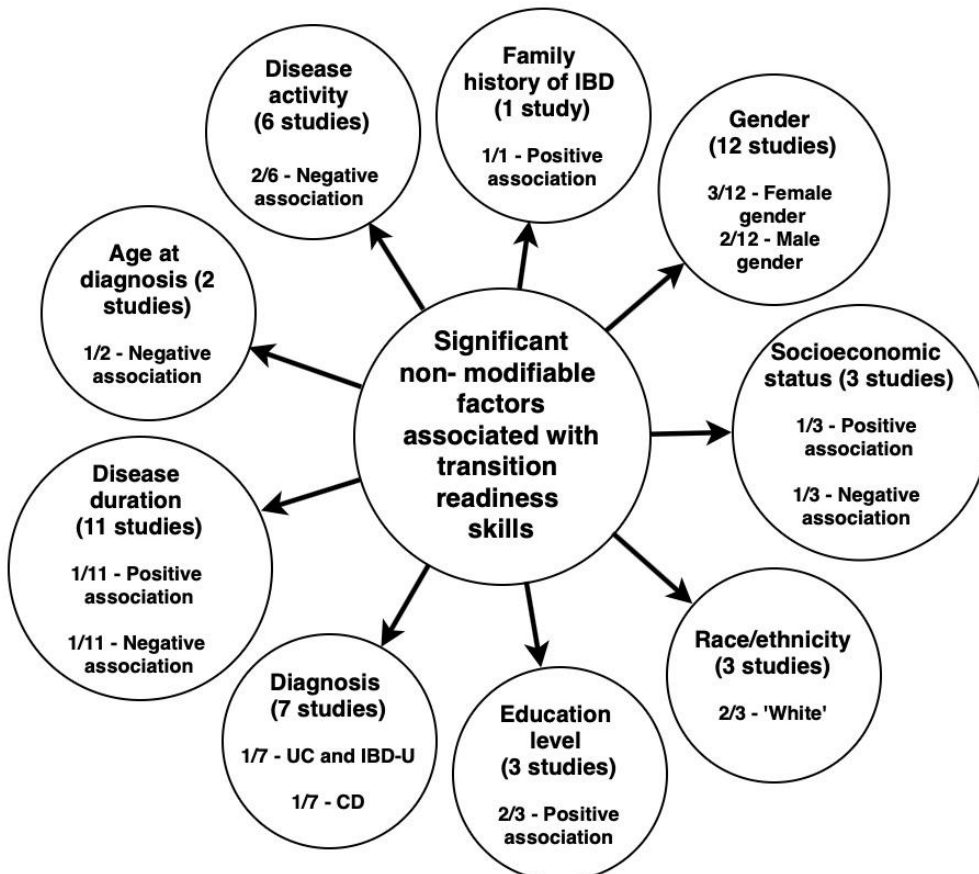
11

12

1 **Figure 2.**



14 **Figure 3.**



24

1 **Figure 4.****How to assess the gaps identified:****• Outcome measurement –**

1. Assessment of self-management using TRAQ
  2. Assessment of knowledge using a subjective measure for example, asking about personal medical history and using the medical record to evaluate accuracy
  3. Survey examining knowledge of IBD itself
- Use of a validated self-efficacy measure to further examine the effects of self-efficacy on the above outcomes
  - Agreeing standardised tools or methods of measuring the influencing factors
  - Assessing how transition readiness skills impact transition outcomes. Evaluating skill levels against a standardised set of measurements for example, appointment or medication adherence, loss to follow-up.