



# Psychological Care for People with Inflammatory Bowel Diseases: Exploring Consumers' Perspectives to Inform Future Service Co-design

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## Abstract

**Background** There is a need to improve psychological care for people with Inflammatory Bowel Diseases (IBD), noting the high psychosocial burden of disease.

**Aims** This study qualitatively explored the views of people living with IBD to help inform future co-design of services that better meet the psychological needs of consumers.

**Methods** Adults with IBD were recruited to attend virtual focus groups to discuss what they want most in an IBD-specific psychological service. The discussions were recorded and transcribed, and data were analyzed using conventional qualitative content analysis. Draft results were summarized midway and reviewed by remaining focus groups and a final expert consumer. A quantitative dataset was created of comment frequencies.

**Results** Thirty-one participants took part in the study: 10 focus groups were held with an average of three participants per group. The analysis identified 254 codes, 38 sub-categories and six categories. Five main categories were identified for an IBD-specific psychological service: *People-Centered Healthcare* (commented on by 90% of participants), *Education and Preparation* (83%), *Social Connection* (83%), *Psychological Input* (93%), and *Accessible Services* (97%). Results were summarized in a set of proposed clinical guidelines.

**Conclusions** The findings of this study identify important insights from people living with IBD regarding priorities for psychological services. IBD services should focus on improving education, addressing social connection, and integrating

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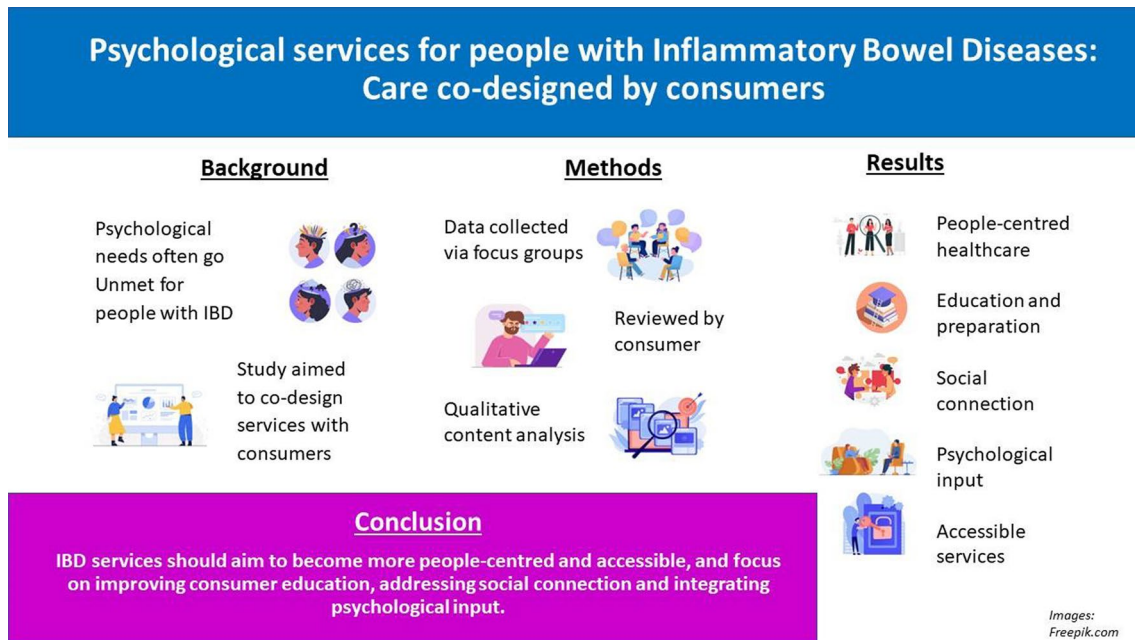
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psychological input, as well as becoming more people-centered and accessible. It is hoped that IBD services consult the proposed clinical guidelines to inform co-designed service improvements.

## Graphical Abstract



**Keywords** Inflammatory Bowel Diseases · Psychological factors · Co-design

## Introduction

Inflammatory Bowel Diseases (IBD) such as Crohn's disease (CD) and ulcerative colitis (UC) can profoundly negatively affect a person's quality of life [1]. Symptoms such as diarrhea, urgency, pain and fatigue are chronic and can hinder daily functioning. Psychological problems like anxiety and depression are highly prevalent [1]. Other common psychosocial issues include trauma, body dissatisfaction, disordered eating, social isolation and sexual dysfunction [2, 3]. Additionally, psychosocial problems are associated with greater healthcare burden and increased disability in IBD [4, 5].

IBD is best managed with a broad, multidisciplinary approach [6]. Where integrated, psychological care has been associated with reduced unplanned healthcare use, increased treatment adherence and improved mental health and quality of life [4, 7]. However, psychological care is often absent from IBD care settings [8–10]. Recent research has highlighted a desire for greater recognition of psychological concerns [11], more mental health discussion with IBD clinicians [8] and increased access to treatment options [12].

To improve IBD healthcare, psychological services and supports need to be developed, but the specific preferences and priorities of IBD consumers for these services

are unknown. Increasingly, consumers are being engaged directly in public health policy and service development, to better capture need, solve problems and produce effective, targeted products [13]. Co-design is a type of consumer partnership in which end-users with lived experience actively participate in the process of service design or improvement [13]. However, the use of co-design methodology in IBD services is limited. The current study aimed to qualitatively explore the views of people with lived experience of IBD regarding what is most important in an IBD-specific psychological service. The aim is to identify the “goal standard” for high-quality, targeted IBD psychological services, so that future clinical care can be co-designed and informed by consumers.

## Methods

### Study Design

The design of this study was informed by qualitative content analysis (QCA) methodology. QCA focusses on the content or contextual meaning of language to gain understanding of a phenomenon of interest [14]. QCA is commonly used in

health research, as data are collected directly from participants and analysis is not limited to pre-conceived ideas, so it is suited to exploring the “voice” of vulnerable populations [14, 15]. This methodology was also chosen as the existent qualitative literature on the preferences of IBD consumers for psychological care is limited. Additionally, it allows for quantification of results [16], so that major and minor themes can be identified via the reporting of code frequencies [17]. Focus groups were chosen as the data collection method for this study, as facilitation of participant interaction and discussion allows for in-depth exploration of the topic of interest [18].

## Participants and Recruitment

Eligible participants were adults with a diagnosis of IBD [CD, UC or IBD-unspecified (IBD-U)] living in Australia. Convenience sampling was used, with the study advertised by two South Australian public hospital IBD services and patient organization Crohn’s and Colitis Australia via social media platforms and email. The Principal Investigator (TL) conducted eligibility screening by telephone. Participants were offered an AUD\$25 voucher for their time [funded via TL’s higher degree research (HDR)].

## Data Collection

### Background Survey

Participants completed a brief questionnaire via online survey tool Qualtrics to collect demographic, clinical and psychological care data (see *Online Resources 1* and *2* for an overview of sample characteristics).

### Focus Groups

Focus groups were held virtually using the videoconferencing platform Zoom® [19] to allow participants from broader geographical locations to attend. Participants were allocated to focus groups based on preference and availability. Discussions were audio recorded and transcribed by TL. The focus groups were facilitated by TL—a trained and experienced cisgendered female health psychologist (*M. Psych Health*) who had no prior relationship to participants. Participants were informed TL worked in the IBD field and the study would contribute to HDR. Ten groups were held between October 2022 and April 2023 comprising a total of 30 participants (each group averaging three) and lasting 50–110 min.

The semi-structured focus group guide was pilot-tested with two authors (AC-H, SE)—see *Online Resource 3* for the general structure. Following introductions, participants were informed of etiquette for group discussions and limits

to anonymity given the presence of multiple individuals in a group setting. Discussions centered around an initial open question with prompts used as needed. Data analysis commenced with the first transcription and continued until no new categories were identified (i.e., theoretical data saturation). As codes and categories appeared relatively consistent after six focus groups had been completed, a summary of the main results was prepared to outline the meaning of each category and provide practical examples for clinical care. The final four groups were asked to review and critique this summary, to engage them directly in the interpretation and analysis process. Participants were given an opportunity to review the transcripts after attendance (no major revisions were made).

## Consumer Review

Following completion of focus groups, the final participant recruited (P31) was invited to review a one-page updated outline of the key categories. Their expertise as a consumer with lived experience was sought to review the final results and provide feedback during two virtual interviews.

## Analysis

Conventional/inductive QCA [14] was used by TL (single coder) to analyze the data. TL familiarized herself with the transcripts and reviewed these for key words. Data were broken down into initial codes and classed into sub-categories and then over-arching categories using software program Nvivo [20]. Code names were derived from the data. As above, participants in latter focus groups and the final expert consumer were invited to share their feedback on the key result categories. An audit trail was kept recording progression of data collection and analysis. A quantitative dataset of code frequencies by group, individual and overall was created. To check coding reliability [21], two authors (AC-H, SE) reviewed the coding of a data subsample (20% each) following analysis of six focus groups. All authors approved the results.

## Results

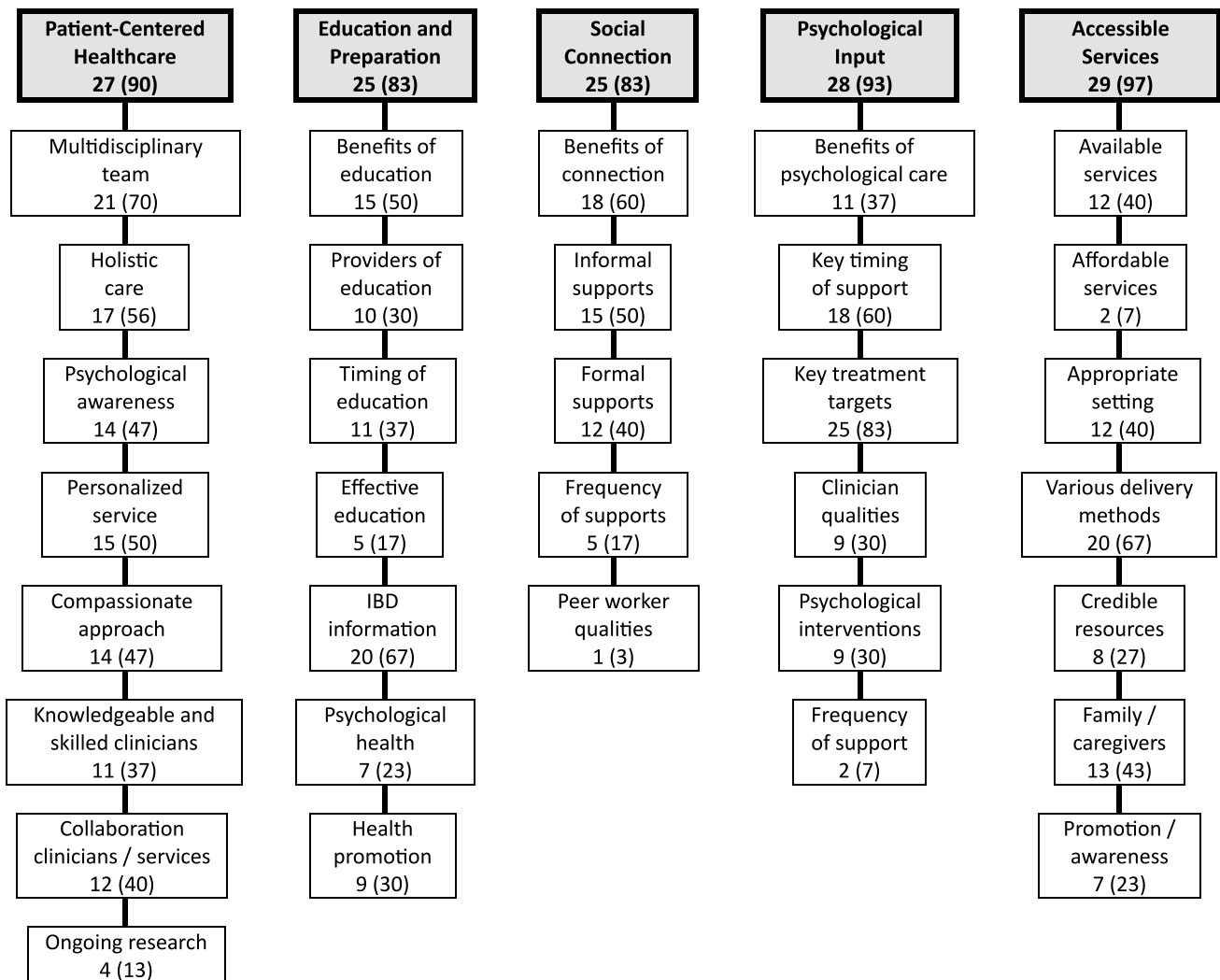
### Participant Sample

Fifty potential participants registered interest and were contacted: of these, eight were lost to follow-up, seven were deemed ineligible (e.g., no IBD diagnosis) and one withdrew. The remaining 34 eligible participants provided written consent. Three dropped out before focus group participation ( $n = 2$  no response,  $n = 1$  no suitable time).

The final participant sample comprised 31 individuals [10 identified as-men and 21 identified as-women (68%)] aged between 21 and 80 years (median = 46 years, IQR = 24), most from South Australia (84%). Sixteen had CD and 15 had UC. Disease duration ranged from 1 to 54 years (median = 7 years, IQR = 13). Twenty participants (65%) were in remission and 19 (61%) received IBD care in a public hospital setting. Most reported typically never being asked about mental health by their IBD clinician (71%), wanting to be asked more frequently (81%), and not having access to psychological care in their IBD setting (84%). Ten participants (32%) were currently participating in psychological care, 8 (26%) had previously and 13 (42%) had no experience. *Online Resource 1* summarizes all participant characteristics and *Online Resource 2* participants' experience with psychological care.

## IBD Psychological Care

The analysis identified 254 codes, 38 sub-categories and 6 overarching categories. A complete list of codes, sub-categories and categories with associated frequencies is provided in *Online Resource 4*. Five main categories described what is most wanted in an IBD-specific psychological service: (1) *People-Centered Healthcare*, (2) *Education and Preparation*, (3) *Social Connection*, (4) *Psychological Input*, and (5) *Accessible Services*. An additional sixth category was identified to summarize codes about psychologically unsupportive care: (6) *Psychologically Unsupportive*. Figure 1 illustrates the key categories and sub-categories. Table 1 sets out illustrative quotes for the main categories and sub-categories.



**Fig. 1** Overarching categories and sub-categories with associated participant frequencies  $n$  (%). Note frequency refers to number of participants whose comments contributed to the identified category or sub-category, with percentage based on total across all focus groups ( $N=30$ )

**Table 1** Illustrative quotations for IBD psychological care over-arching categories and sub-categories

<b>Category</b>	<b>Sub-category</b>	<b>Illustrative quotations</b>
<b>People-Centered Healthcare</b>		
	Multidisciplinary team/care	<i>“I think it'd be nice to have like... a dedicated place where maybe they did... all these other things together... counselling, group therapy, a dietitian, you know... A whole center for IBD where there was like... different clinicians doing different treatments”</i> (P11, FG3)
	Holistic model of healthcare	<i>“So, to me it should be more of an awareness that when you first get it you should be able to see like a clinical nurse or someone... that can look at other areas and maybe say to you ‘you know, you could go here, or you could go there, or there's this available...’”</i> (P27, FG8)
	Psychological awareness and action	<i>“The gastroenterologist needs to be able to acknowledge when a patient needs psychological care, as many will at some point... They just need to have the right people in place to send you – the gastroenterologist should be equipped to know who I can see”</i> (P30, FG10)
	Knowledgeable and skilled clinicians	<i>“So, there is a lot of education that would be... for the people that are in care. The doctors, the specialists, they don't seem to be either aware [of] or educated or concerned [about]... this sort of stuff at all... It would be introducing that, adding that to people who are studying to become specialists in this area”</i> (P5, FG5)
	Collaboration between clinicians/services	<i>“I actually think the IBD clinic should be involved, or the cancer clinic should be seeking more help from the IBD clinic...”</i> (P20, FG2)
	Compassionate and responsive approach	<i>“My doctor's great... he puts his hand on mine and says ‘oh, I'm sorry to hear you're not feeling too well, you've had bit of an uphill battle’ – you know, it gives you that little bit of comfort”</i> (P27, FG8)
	Personalized/targeted approach	<i>“It's critical that there's stepped levels of care. So, a health educator... that's the beginning, and then some... may need counselling, they may or may not need a psychologist, they may or may not need psychiatric support... It's really crucial that there's no attempt to create a single psychological support approach. It's got to have scope for... a higher level of care as their needs go there”</i> (P7, FG4)
	Ongoing research	<i>“More research about how your gut affect your mental health”</i> (P26, FG9)
<b>Education and Preparation</b>		
	Benefits of education	<i>“Maybe talking about whether there were different options [re medications], which I now know that there were... they just were never communicated to me... that might have helped... I like to be informed”</i> (P4, FG1)
	Providers of education	<i>“An IBD nurse... rang me each week and chatted to me, and asked how I was going... Just that extra support there... the nurse has the time to chat to me if I have any questions and that sort of thing”</i> (P8, FG3)
	Timing of education	<i>“At the beginning... you're given a couple of pamphlets, or you're told a little bit and that's it and [you] go off and you're kind of overwhelmed! It would be nice to have... a call the next day... when you're full of questions and trying to figure out what's going on!”</i> (P29, FG9)
	Effective education	<i>“The other thing about education is consistent messages”</i> (P25, FG8)
	IBD and management	<i>“I'm still sort of struggling to know what I really shouldn't be eating and maybe what I should be eating... it's always better when you talk to someone... they have some insights that you may not be able to get out of the book yourself”</i> (P23, FG7)
	Psychological health	<i>“The prevalence of mental health concerns and issues related to IBD... something that I never had heard of before. I thought, wow if someone told me that... that would have made me feel a little bit more normal, where I was at the time, what I was going through”</i> (P19, FG3)
	Health promotion	<i>“So, education, scene setting, even just you know, talking about what you need to fit into your life when you have a chronic illness... medication, sleep um, you know, other things that all contribute to you having, I guess, a good baseline health, so that you can deal with whatever is coming your way. That sort of thing is I think helpful”</i> (P4, FG1)
<b>Social Connection</b>		
	Benefits of connection	<i>“Support just in an online forum for other people with IBD helps me realize I'm not too bad... To hear that other people have it and may have it worse – not that you'd wish that on anybody – but to just hear what other people's stories are, makes you feel a bit more okay. A lot of people are dealing with this, not just me... it's nice to have that connection”</i> (P29, FG9)
	Formal social supports	<i>“One of the interventions that I think could be useful... is a mentoring relationship”</i> (P25, FG8)
	Informal social supports	<i>“Definitely family support, like you know, friend support... makes a huge difference”</i> (P1, FG6)
	Peer support worker qualities	<i>“As long as the peer supporter is well, living with the illness, well as best they can... promoting wellness and things like that, to the guidelines”</i> (P28, FG8)

Table 1 (continued)

Category	Sub-category	Illustrative quotations
	Frequency of social support	<i>"I'd love to do some type of... monthly peer support catch-up or something... I know life is busy, you might not be able to get to every month... but that would be good"</i> (P12, FG2)
<b>Psychological Input</b>		
	Benefits of psychological input	<i>"Just to have someone who has that understanding to talk through everything with you. And to yeah, I guess someone to help follow your journey with you... because that was a lot to take in when you have little to no understanding... To help process everything"</i> (P22, FG4)
	Key times for psychological input	<i>"Probably at diagnosis would be an important time, because you have to accept that you have a lifelong illness and a chronic illness. And I think, having someone to talk through that with you is important"</i> (P14, FG2)
	Key treatment targets	<i>"It gets kind of embarrassing like, because I have some changes down there that I haven't felt comfortable with being intimate with anyone for quite a while. So, I guess you know, learning to deal with that or learning to accept that has been challenging..."</i> (P11, FG3)
	Clinician qualities	<i>"I think that's really important – to have the knowledge of the medical side of things, and then, like you can specialize your psychological treatment according to that"</i> (P14, FG2)
	Interventions and approaches	<i>"Pain management through hypno(therapy), yeah hypno I had done, and that's been very helpful"</i> (P1, FG6)
	Frequency of input	<i>"It doesn't need to be very regular sessions either... once a month"</i> (P3, FG1)
<b>Accessible Services</b>		
	Available	<i>"I think availability, for you know, if you need to ring someone out to talk to them"</i> (P21, FG6)
	Affordable	<i>"My first thought was free clinical psychology services!"</i> (P15, FG4)
	Setting	<i>"As long as it's sort of like where you go for your treatment. It would be better for the people so they're not traveling here there and everywhere"</i> (P10, FG1)
	Various delivery Formats	<i>"But any kind of telehealth service... I think we, you know, in lockdowns we're sort of used to... dialing into calls like this... So, I'm not too fussed how it's delivered, as long as there's someone on the end of the phone or at the end of a video call!"</i> (P3, FG1)
	Credible resources	<i>"Information like those should be aggregated at some place, which will help other people definitely"</i> (P2, FG1)
	Family members	<i>"I think for me, a gold standard would also include my partner because he watches... he has no idea how to help me. And... he can't help, there's nothing he can do in those darker times... So, I think some information and just some support for your partner"</i> (P13, FG4)
	Promotion and awareness	<i>"So, I feel more promotion of the resources, if they were to be created... more availability or promotion of them is important as well"</i> (P14, FG2)

P participant number, FG focus group number

## People-Centered Healthcare

In discussing what constitutes a “gold standard” IBD psychological service, 27 participants referred to the need for healthcare to be more people-centered. For example, 21 (70%) stated the IBD service would ideally be multidisciplinary and include a psychologist, a dietitian and dedicated nursing staff. Seventeen (56%) wanted to see a broader range of health needs addressed, such as mental health, diet and comorbid functional symptoms: *“there are other aspects of this disease that affect your health in other ways...”* (P11, FG3). Fourteen participants (47%) mentioned addressing psychological needs directly, with eight suggesting a standard early assessment: *“not everybody needs psychological intervention, but I think the service should definitely be offered and be part of the diagnosis program, I mean, without option”* (P24, FG7).

People-centered healthcare also referred to factors that are indirectly supportive. Eleven participants (37%) highlighted the importance of clinicians being experts in IBD and knowledgeable in common comorbid issues (such as mental health). A compassionate approach was mentioned as crucial by 14 (47%): *“I just would have liked to have had a kind word at the beginning”* (P27, FG8). Fifteen (50%) wanted greater consideration of individual factors such as age and gender. Better collaboration between clinicians, as well as between services, would likely reduce unnecessary stress ( $n = 12$ , 40%). Four participants (13%) even raised the value of ongoing research, to ensure IBD management continues to advance.

## Education and Preparation

Twenty-five participants (83%) described education as a type of psychological service. Fifteen (50%) discussed benefits, including sufficient information and preparation, reduced anxiety and empowerment. Three participants commented specifically that education is therapeutic: “*even though it's like it's not meant to be psychological support, it does provide psychological support, because we feel that we are listened [to]... and that someone is actually on top of it*” (P1, FG6). Ten (33%) wanted education to be provided by multiple clinicians, not just their IBD doctor [e.g. (re IBD nurses) “...they are good, you know, in killing your anxiety” P9, FG6].

Eight participants (27%) reported that education is particularly vital at diagnosis, when IBD is most unfamiliar. Twenty (67%) said more information on IBD is required: “*having a way of when people have been newly diagnosed... providing the right level of education... A proper baseline amount of information about the condition*” (P4, FG1). IBD medications and side-effects, coping strategies, surgery, complications and diet were also identified as needing greater explanation. Psychological health and health promotion were mentioned by 7 (23%) and 9 participants (30%) respectively, as topics where further education is desired.

## Social Connection

Most participants ( $n=25$ , 83%) talked about the ideal psychological service facilitating social connection. Benefits discussed by 18 (60%) included belonging, relatability, sharing of ideas, reassurance and hope; for example: “*It's a very lonely journey... you really feel you're running your own race... People who've got lived experience with Crohn's should always be connected... so you can feel that you're not just going on this journey alone*” (P3, FG1). Fifteen participants (50%) mentioned the usefulness of informal supports, such as family and friends, lived experience stories and consumer gatherings: “*it was a meet-and-greet, you know, coffee and a bit of food. It was more like an enjoyable meet*” (P27, FG8). Formal service ideas were provided by 12 (40%) and included peer advice, activity groups, social prescription and mentoring: “*a peer support group... can help make connections and have that sort of sense of community*” (P18, FG5). One participant also listed key requirements for a peer support worker, such as living well with IBD, being knowledgeable and providing hope.

## Psychological Input

Most participants ( $n=28$ , 93%) commented on psychological input. Eleven (37%) listed benefits such as having someone to talk to, reducing distress, receiving emotional

validation, and learning practical coping tools. One referenced her own experience: “*I think being able to talk to someone in a non-judgmental space about something that... is pretty embarrassing. It's just really good... the psychologist that I spoke to just had a way of making it all okay and just comfortable. And I just felt safe... being able to talk really frankly with someone about all the nitty, gritty, yucky details*” (P19, FG3). Eighteen (60%) highlighted critical times for psychological input, most notably at diagnosis, acute disease flares and surgery; four also pointed out that it is important any time it is wanted and needed.

Psychological treatment targets were mentioned by 25 participants (83%). Examples of psychological issues included anxiety, stress, depression, adjustment, embarrassment, body dissatisfaction, trauma, coping and outlook: “*I think positive thinking has a lot to do with how you cope*” (P17, FG2). Social targets were communication, social limitations and intimacy and relationships. IBD concerns included managing symptoms, surgery, medications and uncertainty. One participant illustrated the importance of psychological input when describing her experience in hospital: “*When you're in hospital and feeling scared and afraid and not sure about the future, I think it would be helpful to have like a psychologist come in and talk to you. And when you're going through those surgeries and that, because it's quite traumatic... Looking back to that moment, I was really scared... there was no psychological support, and I feel like that's really needed*” (P14, FG2).

Nine participants (30%) outlined the positive qualities they would like in a psychologist, including empathy and being a companion on the journey: “*...empathize and help people process this whole new world of Crohn's and IBD... help you navigate your own journey, holding your hand*” (P15, FG4). IBD knowledge was also preferred: “*with the trauma that some people have been through... you really want someone that can relate to you – maybe not from lived experience, but from at least knowledge of the medical side*” (P6, FG3). Nine (30%) showed an awareness of types of psychological interventions. The intervention mentioned most was hypnotherapy ( $n=4$ , 13%). Pastoral care and exercise were also noted as psychologically supportive approaches by two and one participant/s, respectively.

## Accessible Services

All but one participant commented on service accessibility (97%). Accessibility included greater availability of clinicians ( $n=12$ , 40%). The most desired setting for psychological care was integrated within the IBD team ( $n=9$ , 30%), although one participant advocated for an external location. Twenty (67%) listed a variety of delivery formats such as face-to-face, phone, telehealth, online and via email, to cater to a variety of needs and preferences. Eight participants

(27%) commented that IBD psychological services should be complemented with credible resources via consumer events, videos and written materials. Thirteen (43%) highlighted the importance of partners and family members also accessing psychological services: “*psychological help for my wife and my children, and even further back in the early days, for my parents, would be a fantastic thought... a very, very good thing*” (P16, FG2). Seven (26%) also emphasized the need for services to be promoted widely, so that people know what is offered and how it can be accessed.

### Psychologically Unsupportive

A sixth overarching category summarized factors that are unhelpful for mental and emotional wellbeing [commented on by two-thirds of participants ( $n=2$ , 67%)]. For example, 14 (47%) referred to healthcare experiences that negatively affected their emotional wellbeing: “*they don’t ask how you have been feeling, or how you feel. There’s no care or bedside manner there at all... I’m just a number*” (P27, FG8). Eight participants (27%) described the implications of ineffective education, including receiving either too little or too much information. Experiencing negative effects of peer support was also mentioned by 8 participants (27%); for example, one stated “*there’s also the possibility of being pulled down... One I went to [support group], I was overwhelmed*” (P25, FG8). Six (20%) commented on the absence of psychological care and 4 (13%) highlighted barriers to access. Essentially, these subcategories reflected the reverse of the abovementioned five main categories for IBD psychological services (see *Online Resource 4* for further detail).

### Consumer Review

The expert consumer’s review of the results was confirmatory. The importance of each category was reinforced, as well as the topic of IBD psychological care: “*The clinician who’s looking at this, they need to realize it’s a duty of care... It’s really important... for that gastro or that head person to lead the way on making sure that psychological services are put into their care... It’s pertinent on someone’s health, it’s huge actually!*” (P31). The consumer queried whether the first category *People-Centered Healthcare* should be split into two, noting several sub-categories refer to consumers while others relate to clinicians. After discussion with co-authors, the category was kept intact as it was thought the sub-categories were still related.

### Clinical Recommendations

Proposed clinical practice guidelines were drafted as a useful way to summarize the results and provide IBD clinicians with practical recommendations for IBD psychological care

(see *Online Resource 5*). The guidelines were drafted by the PI based on the five key categories and their respective sub-categories—an expansion of the previous result summary discussed by latter focus groups. The expert consumer provided specific feedback and suggestions for the drafting of the guidelines.

## Discussion

This qualitative study is the first to explore the priorities of IBD consumers with respect to tailored psychological services for the purpose of co-design. The findings highlight clear themes for the types of services desired by people with IBD, as well as care structures and delivery mechanisms that support psychological health. In this study, participants were asked about the ideal, perfect or “gold-standard” IBD psychological service, and the results emphasize the value of broader care components beyond individual psychological therapy.

Three of the overarching categories referred specifically to interventions: *Education and Preparation*, *Social Connection* and *Psychological Input*. These services have the potential to improve psychological wellbeing in different ways. For example, education improves consumer knowledge and understanding, which have been associated with higher levels of self-efficacy, medication adherence and treatment engagement [22]. In IBD, education has also been found to reduce psychological distress and improve self-management and coping [23]. Education has the potential to reduce the psychological burden of IBD.

Social connection is psychologically helpful because it offers people with IBD various emotional, practical and informational supports. The importance of peer connection is not surprising, as it is well-established that relationships and connectedness are protective for both mental and physical health [24]. In contrast, loneliness and isolation are risk factors for anxiety and depression, elevated inflammation and mortality [25]. Of note, informal social interactions (e.g., support from family and friends) were mentioned by more participants than formal activities. Thus, as a service, social connection may be about exploring and reinforcing use of a person’s current social network, or it may involve more deliberate referral to structured peer supports.

Psychological input has the potential to directly improve mental health for IBD consumers by reducing distress and increasing coping. The growing literature on psychological interventions in IBD shows short-term improvements in mood and anxiety and more consistent benefits for quality of life [26]. While some of the input discussed by participants could be provided by other IBD clinicians (e.g., “*being able to talk really frankly with someone about all the nitty, gritty, yucky details*” [P19, FG3]), the overall desire was



for a dedicated IBD psychologist or mental health provider. Psychological intervention can treat IBD-related distress, and (as recognized by some participants) support self-management and health promotion which are important for those living with a chronic illness.

The other two main categories referred to the structure and delivery of health services: *People-Centered Healthcare* and *Accessible Services*. The message underpinning people-centered healthcare is that there are certain clinician qualities and healthcare practices that promote emotional and mental wellbeing. While past research is mixed, some evidence suggests that people-centered care is associated with greater treatment satisfaction and self-management [27]. When people are cared for by a multidisciplinary team of knowledgeable clinicians in a holistic, collaborative and compassionate manner, it makes sense that they would feel more psychologically supported.

Making services and interventions accessible is also important. Only 16% of study participants reported current access to psychological care in their IBD setting, consistent with past research [8, 10]. Of note, nearly half (42%) raised access for family members and partners—this is in line with a recent systematic review which identified the need for greater education, social support and mental health input for IBD carers [28].

This study's findings are consistent with recent research. For example, a review of the UK national IBD standards [9] highlighted the need for greater education, holistic care, access and multidisciplinary services. They also identified a desire for more educational programs, resources, communication between IBD services and external providers, and support with mental health. Another study of consumers in the UK and Australia [11] identified three similar themes: vicious cycle of IBD and psychosocial health, the need for biopsychosocial health integration and stigma of hidden disease. Further, a Scottish co-design study found three themes important for improving IBD care: quality of life, IBD clinicians and better access, and explicit IBD care pathways [12]. The closeness of our findings with these studies investigating IBD care more broadly (i.e., not psychological services specifically) is particularly telling: it emphasizes the importance of care quality for psychological health and wellbeing.

In addition, there are parallels between this study's results and current published IBD quality of care standards. For example, the Australian IBD Standards [6] include having multidisciplinary care, a people-centered approach and education. The presence of a psychologist and early psychological assessment are also consistent with UK IBD Standards [29]. Further, the findings are in line with the priorities of The Australian National Action Plan for IBD 2019 [30]. For instance, *People-Centered Healthcare* is consistent with the priority area of a skilled and accessible multidisciplinary workforce. *Accessible Services* has several sub-categories

in common with the priority area access to responsive IBD helplines. Finally, *Education and Preparation* aligns with the priority area patient knowledge.

Ultimately, the aim of the current study was to ascertain the priorities and preferences of people living with IBD for psychological care to inform the co-design of future services. The proposed set of clinical practice guidelines (*Online Resource 5*) includes improving and/or incorporating the three interventions into IBD management and restructuring or refining practices and delivery mechanisms. It is hoped that IBD services will review these guidelines and work towards adopting the recommendations over time. For example, new care settings could use these guidelines to inform service design, while existing services could use them for improvement initiatives and business cases.

The main limitation of this study is the potential for bias (e.g., interviewer, coder, participant). However, multiple strategies were used to minimize this risk, including pilot testing the focus group guide, code checking by two additional authors and results review by participants. While only one participant reviewed the final results, the categories were the same as those reviewed by the last four focus groups. Participants were self-selected, mostly from one Australian state, and those with online access/literacy. Focus group numbers were also small (due to the challenges of coordinating availability for multiple people). However, participant views are likely transferable given the similarities with other data sources [9, 11, 12]. Future research may include IBD service audits or consumer surveys to compare current practices with the proposed guidelines to determine development priorities. Services that currently incorporate psychological care might qualitatively explore consumers' experiences to gain insight into specific benefits and challenges. Further development of the proposed clinical guidelines is also recommended, to gain further input from both consumers and clinicians.

In conclusion, this study provides valuable insights from people living with IBD and clinical recommendations for co-designing services that better address psychological health and wellbeing. Specifically, IBD services should emphasize consumer education, social connection and psychological input. Beyond this, IBD services should work towards becoming more people-centered and accessible. It is hoped that the proposed guidelines will be used by IBD clinicians to better support the psychological health of IBD consumers.

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**Data availability** The data underlying this article cannot be shared publicly due to participant privacy. The data will be shared on reasonable request to the corresponding author.

## Declarations

**Conflict of interest** TL: declares speaker's fees from Mindset Health. AC-H, SE, AM-W: all declare nil conflicts of interest. KL: declares speaker's fees, advisory Board fees, and/or conference travel/registration support from: Abbvie, Bristol Myers Squibb, Chiesi, Dr Falk, Ferring, Gilead, Guidepoint, Intercept Pharmaceuticals, Janssen-Cilag, MSD, Norgine, Pfizer, Sandoz, Takeda, the RAH Research Fund. JMA: declares speaker's fees, advisory Board fees and educational/research grants paid to her institution from: Abbott, AbbVie, Allergan, Anantara, AstraZeneca, Bayer, BMS 2020, Cellegene, Celltrion, Falk, Ferring, Gilead, Hospira, Immuninc, ImmunsanT, Janssen, MSD, Nestle, Novartis, Pfizer, Sandoz, Shire, Takeda, Vifor, RAH research Fund, The Hospital Research Fund 2020–2022, The Helmsley Trust 2020–2023. TL, AC-H, SE, AM-W, LR and JMA all declare that they have no conflicts of interest or financial disclosures for this research.

**Ethical approval** This study was approved by the Human Research Ethics Committees (HREC) of the Central Adelaide Local Health Network (CALHN; Ref#1660) and Deakin University (DUHREC Ref#2022-236).

**Informed consent** All participants provided written informed consent to participate in this study.

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