Centre for Global Health and Equity

Crohn’s & Colitis Australia

Final Report – Ophelia Project

Consumer Education and Awareness of Inflammatory Bowel Disease

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Executive Summary

This is the final report of the Crohn's & Colitis Australia (CCA) Consumer Education and Awareness of IBD (CEA-IBD) project based on the Ophelia (Optimising Health Literacy and Access) process. It presents a brief summary of the entire project and the findings from the second evaluation survey of the updated CCA website. The evaluation clearly indicates that people living with IBD found the website resources trustworthy and useful in supporting their self-management of health and wellbeing. About two thirds of survey participants reported changing their behaviour in multiple ways after viewing information on the new CCA website.

Projections indicate that, by the year 2030, 283,930 Australians will be living with inflammatory bowel disease (IBD) (Kaplan & Windsor 2021). Crohn's & Colitis Australia (CCA) recognised and prioritised the need to understand the health literacy strengths and challenges of people living with IBD, and their carers, to improve and develop information and resources to support self-management of IBD. CCA commissioned the team at the Centre for Global Health and Equity (CGHE) at Swinburne University of Technology as research partners for the 4-year project (2020 to 2023) to apply the Ophelia (Optimising Health Literacy and Access) process. This report presents the Ophelia project findings of the CCA Consumer Education and Awareness of IBD (CEA-IBD) project.

There are three phases to the Ophelia process. Briefly, these consist of 1) needs assessment and generation of action ideas, 2) development and testing of health literacy actions, and 3) implementation and evaluation.

Ophelia Phase 1 – Needs assessment to identify strengths, needs and action ideas

A comprehensive survey covering health literacy and demographic data informed the development of a series of vignettes of typical people with IBD. The vignettes were then used in ideas generation workshops that were held online with people with IBD, their carers, and health professionals working in gastroenterology, mental health and other IBD-related fields of health. Eight evidence-based vignettes revealed health literacy strengths and challenges and a range of different life circumstances for people with IBD and carers of people with IBD. The vignettes facilitated in-depth discussions that generated hundreds of variations on ideas about what is currently being done, or what could be done to support people living with IBD. As intended, the ideas covered the personal, social and medical contexts of people living with IBD and ranged from provision of clear information about lifestyle and medicines and the need for CCA to advocate for IBD to be included in national funding schemes to suggestions for libraries to provide information about IBD support for people living in rural and remote regions of Australia, along with many other ideas.

Ophelia Phase 2 – Select, plan and test health literacy actions

The focus of Ophelia Phase 2 was on developing the capacity of people with IBD to self-manage their health through improvements to and expansion of the range of practical and implementable information and support resources that CCA provides. The CHGE team supported CCA to conduct a rating and prioritisation process internally and with the project advisory group that helped to direct the development of the new CCA website, the resources needed for the website, actions for other existing CCA projects, and strategic direction for the organisation over the next 5 to 10 years. The new CCA website was launched in March 2022 with health information about Crohn's disease and ulcerative colitis, including symptoms, diagnosis and treatment, and information about living with Crohn's and colitis, including exercise, nutrition, psychological health, fatigue, travel, fertility and pregnancy, and sexuality. An IBD Service Locator was also launched to help people find an IBD service near them. In August 2022, Survey 2 (the first evaluation survey) was released on the CCA website to collect data about users' experiences of the new website resources.

Ophelia Phase 3 – Implement, evaluate and improve health literacy actions

As ongoing improvement to the website, CCA progressed the development of resources and, between January and August 2023, uploaded new resources to the website. These resources included information for young people and parents or carers, differentiating between IBD and Irritable Bowel Syndrome, financial information, rural and remote specific information, communicating about IBD information, a poster for healthcare professionals to promote CCA information and services to people with IBD, additional nutrition information on a variety of topics, three animation videos targeted at managing IBD, information for schools and workplaces, and translation and cultural adaptation of existing resources so as to better serve people from diverse cultural backgrounds. Ophelia Phase 3 is a process of implementing health literacy actions and checking the actions are responding to the needs identified in Phase 1.

As well as providing a final overview of all phases of this project, this report describes the activities and outcomes of Survey 3 (the second evaluation survey) to further assess users' experiences of CCA's resources.

Evaluation findings

On average, a statistically detectable change in health literacy scores in people visiting the website was not observed, according to the HLQ skills and ability questionnaire over the study period. This minimal change was expected given the small sample size, and it does not reflect the quality of improvements made and resources developed by CCA. What the evaluation did find was that survey participants trust the CCA resources, they feel the resources are well organised, and, importantly, nearly two thirds of the Survey 3 participants made changes to improve the way they self-manage their health and wellbeing after reading information on the CCA website, which is a good reflection of improvements in health literacy. Some of these participants made between 3 and 10 changes, including changes in behaviours to do with their diet, medication or treatment, communicating with family and friends about their health, and their physical activities.

An audit of the newly created materials for the website and previous webpages identified substantial improvements in the understandability and actionability of patient or consumer education materials.

Overall, the evaluation demonstrated that a wide range of people took part in the development of the resources through participating in surveys and attending workshops. Some groups were potentially underrepresented, including younger people and people from a wider range of culturally diverse backgrounds, who are frequently challenging to recruit into research projects in this setting.

Conclusion

Overall, the website evaluation feedback indicates that the CCA website is highly organised, informative, and has changed how people self-manage their health conditions and improve their wellbeing. Some opportunities for improvement were identified, including information for more diverse people and perhaps more stories to increase the sense that the many perspectives of people with IBD are being represented. Specifically, website resources for older people and people who have been living with IBD for more than 10 years are needed. Future research directions could include recruitment of additional younger people and people from a wider range of culturally diverse backgrounds because these groups were not strongly represented in the project.

Expectations about true co-design of this research were met and also evolved from the beginning of the project in early 2020, and this is an important outcome of the work completed. The Ophelia process facilitated the co-design nature of the project and supported the dedication of all stakeholders to the conduct of research with integrity and with and for the people served by CCA. This project has developed a research partnership and co-design methodology to facilitate improved working relationships between academia and industry, leading the way for future research opportunities and accelerated positive impact on people living with IBD and other health conditions.

References

Kaplan, G. G., & Windsor, J. W. (2021). The four epidemiological stages in the global evolution of inflammatory bowel disease. *Nature reviews Gastroenterology & Hepatology*, 18(1), 56-66. https://doi.org/10.1038/s41575-020-00360-x

Introduction

The Australian Government published the IBD National Action Plan in 2019. The purpose of the Plan was to identify the most important short to medium term actions that will improve equitable access to high quality health care for people living with IBD in Australia. A priority of the Plan was to improve patient knowledge through the development of self-management focused information materials. Crohn's & Colitis Australia (CCA) was funded by the Australian Government through a Public Health and Chronic Disease Program grant to conduct the Consumer Education and Awareness of IBD (CEA-IBD) project. The project sought to better understand and respond to the health literacy needs of people living with inflammatory bowel disease (IBD) and their carers, with a particular focus on facilitating evidence-based improvements in the IBD self-management information and resources that CCA provides. The Centre for Global Health and Equity (CGHE) at Swinburne University of Technology was commissioned by CCA to support this process and, specifically, to provide research design, data analysis, statistical reporting and evaluation of the project.

This is the Final Report of the project and provides an overview of activities through which the CGHE team applied the three phases of the Ophelia (Optimising Health Literacy and Access) process to achieve the project outcomes. Findings from Ophelia Phases 1 and 2 are provided in detail in Progress Reports 1 to 3 and are summarised in this Final Report, which provides detailed information about the evaluation activities and findings of Survey 3.

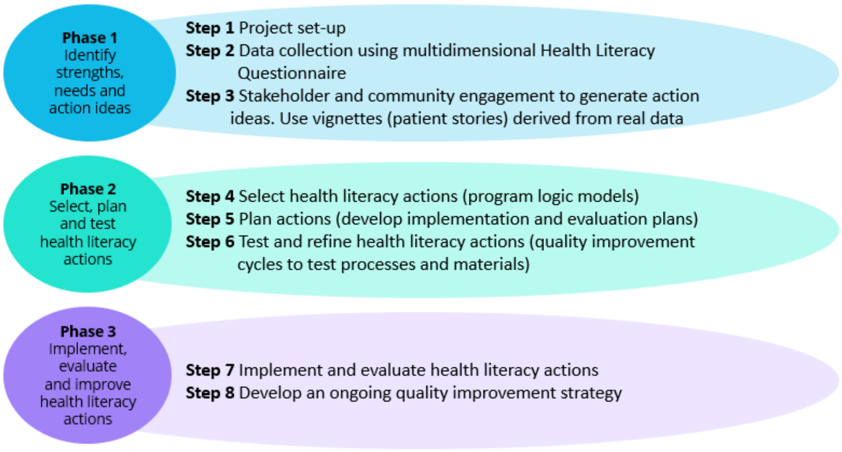
Ethics approval for this project was obtained from the Swinburne University Human Research Ethics Committee (ID: 20202968).

Key project activities

There are three phases to the Ophelia process (Figure 1). Briefly, these consist of 1) needs assessment and generation of action ideas, 2) development and testing of health literacy actions, and 3) implementation and evaluation.

These phases function as a systematic process to elicit a wide range of ideas from a diverse range of people and to then draw together and consolidate the plethora of ideas into targeted, implementable and relevant practical actions to develop health literacy responsiveness. Importantly, Ophelia Phase 1 generates data and ideas using a bottom-up approach with people with lived experience and their health practitioners, and Phases 2 and 3 match the ideas generated to the priorities and strategic plans of organisations, such as CCA, to identify areas in which existing programs can be improved and, if needed, new resources, programs and strategic directions developed and implemented.

Figure 1. The 3 phases of the Ophelia (Optimising Health Literacy and Access) process



This project implemented Ophelia Phases 1 to 3 from March 2020 to September 2023 (Table 1).

Table 1. Summary of key activities of the Crohn's & Colitis Australia Ophelia project

Activities	Outcomes	Completion dates
Phase 1 – Needs assessment to identify strengths, needs and action ideas.		
Step 1 – Project set up		
Collaborative consultation with CCA and the project advisory committee including community members and IBD health professionals.	Identified 3 groups of people to be specifically included in recruitment strategies: young people (aged 15 to 25 years); people living in rural and regional areas; people with diverse cultural backgrounds.	27 April 2020
Collaborative project development.	Weekly and then fortnightly meetings between the CCA and Swinburne project teams.	March 2020 to September 2023
Phase 1 ethics application submitted on 5 June 2020.	Phase 1 ethics approved by Swinburne University Human Research Ethics Committee.	27 July 2020
Step 2 – Data collection and analysis		
Recruitment request to Monash Health submitted on 7 August 2020.	Approval for recruitment via Monash Health Gastroenterology.	24 August 2020
South Western Sydney Local Health District ethics submitted on 13 August 2020.	South Western Sydney Local Health District ethics approval.	17 September 2020
Survey 1 (online and paper) data collection with recruitment through CCA, Swinburne University	Online (Qualtrics): 1,313 surveys Paper (by post): 48 surveys	10 August to 31 October 2020

Activities	Outcomes	Completion dates
and Monash Health in Victoria and Liverpool Hospital in New South Wales.		
Descriptive analysis of Survey 1 data.	953 surveys included for data analysis. People with IBD: n=868 Carers: n=85	November 2020
Cluster analysis conducted to identify people with different health literacy patterns.	Optimal cluster solutions identified: People with IBD: 13 clusters Carers: 12 clusters	November 2020
Interviews with people with IBD and with carers.	17 interviews conducted. People with IBD: 13 interviews Carers: 4 interviews	December 2020 to February 2021
Project protocol manuscript submitted on 21 September 2020.	Manuscript published in BMJ Open. http://dx.doi.org/10.1136/bmjopen-2020-045059	7 August 2021
	Progress Report 1 delivered	**16 Dec 2020**
Step 3 – Stakeholder and community engagement to generate action ideas		
Vignette development based on the survey, interview, and cluster analysis results.	8 vignettes representing the quantitative and qualitative data for discussion in ideas generation workshops and activities.	February 2021
Ideas generation workshops and online activities.	76 people from 6 states and 1 territory took part in 9 workshops and 2 online activities. People with IBD and carers: n=38 Health professionals: n=38	March and April 2021
Analysis of workshop data.	70 ideas within 6 themes.	May 2021
Phase 2 ethics amendment submitted on 19 May 2021.	Ethics amendment approved.	19 May 2021
	Progress Report 2 delivered	**2 June 2021**
Phase 2 – Select, plan and test health literacy actions		
Step 4 – Select health literacy actions (program logic models)		
Cluster analysis abstract submitted to International Society for Quality of Life Research (ISOQOL) conference.	Abstract accepted as poster: *From patient-centred measures to patient-centred interventions: Capturing the heterogeneity of patient groups to inform intervention development*	3 June 2021
Health literacy actions abstract	Abstract accepted as oral	18 June 2021

Activities	Outcomes	Completion dates
submitted to the Global Health Literacy Summit conference.	presentation: *Health literacy actions – perspectives from people living with inflammatory bowel disease (IBD)/carers and health professionals*	
Rating activity for key CCA staff and the project advisory group to rank the 70 ideas.	Online workshop with Swinburne, CCA and project advisory group.	15 June 2021
Prioritisation activities.	CCA core team examined and prioritised the ideas into 3 areas for action, noting that some of the ideas generated are outside CCA's ability to implement: • National leadership • Improve services and access • Improve information, tools and processes for consumers	29 June 2021
Step 5 – Plan health literacy actions		
Develop program logic models.	CCA planned actions within 4 projects: • Product for clinicians to link patients to the CCA website • Digital website improvement • Culturally specific resources • Rural/regional specific resources	September 2021
Develop evaluation plan.	An evaluation plan with short- and long-term goals developed by CCA.	February 2022
Step 6 – Develop, test and refine health literacy actions		
CCA team developed, tested and refined resources according to the 3 action areas and 4 projects.	• Product for clinicians incorporated into another existing project with GPs. • New website development and resources – incorporated information and resources for specific groups of people.	September 2021 to July 2022
Health literacy survey and consumer information scan abstract submitted to Australian Gastroenterological Week.	Accepted as a poster presentation: *National assessment of health literacy to identify the needs of people with inflammatory bowel disease*	September 2021
Phase 3 – Implement, evaluate and improve health literacy actions		
Step 7 – Implement and evaluate		
Build CCA website with new resources based on findings from	New website with new resources launched.	9 March 2022

Activities	Outcomes	Completion dates
Ophelia Phase 1.		
Phase 3 ethics amendment submitted on 24 June 2022.	Ethics amendment approved.	24 June 2022
Survey 2 data collection with recruitment through CCA.	Online: 230 surveys	2 Sept to 15 Nov 2022
Descriptive analysis of Survey 2 data and comparison with Survey 1 data where possible.	148 surveys included for data analysis.	December 2022
	Progress report 3	**20 January 2023**
Step 8 – Develop ongoing quality-improvement strategies		
Ongoing development of resources for the CCA website.	New resources added.	January to August 2023
Project extension amendment submitted to Swinburne HREC on 18 May 2023 (original project end date was 29 June 2023).	Ethics amendment approved.	18 May 2023
Survey 3 data collection with recruitment through CCA.	Online: 239 surveys	22 July to 30 August 2023
Descriptive analysis of Survey 3 data and comparisons with Surveys 1 and 2 where possible.	173 surveys included for data analysis.	September 2023
Health literacy interventions abstract submitted to Australian Gastroenterological Week.	Accepted as a poster presentation: *Developing IBD consumer health literacy using the Ophelia process*	September 2023
	Final Report	**29 September 2023**
Final report to Swinburne HREC is due 30 September 2023.	In progress	Will be submitted on completion of the project Final Report
	Project end date	**30 September 2023**

Ophelia Phase 1

The first phase of the Ophelia process involves assessing the health literacy strengths and challenges of people with IBD and their carers. For the CCA project, this phase had two objectives:

- Identify the health literacy profiles of people in Australia who are living with IBD, and the profiles of their carers, and
- Identify the factors that influence their engagement with health information and services, especially in terms of how these factors affect their management of IBD.

The CGHE team started on the project in late March 2020. A structured consultation with the CCA team and the Project Advisory Group found that three groups of people in particular needed to be included in the recruitment for data collection: young people (aged 15 to 25 years), people living in rural and regional areas, and people with diverse cultural backgrounds. Fortnightly meetings between the Swinburne and CCA teams and monthly meetings with the Project Advisory Group facilitated collaborative project development and implementation.

Ethics for Phase 1 was approved by Swinburne Human Research Ethics Committee (HREC) on 27 July 2020. Many amendments were made by the CGHE team to the original approved ethics protocol in order to accommodate the iterative nature of the collaborative co-design process of the project.

Survey 1

The CGHE team set up and managed the survey on the Swinburne Qualtrics platform and distributed the link to CCA to host the survey on the CCA website. Data were collected from 10 August to 31 October 2020 online via the CCA website, through CCA's professional networks, and by paper surveys posted to members of CCA who were on the CCA mailing list as receiving a paper copy of the CCA newsletter. Data were also collected through Monash Health and Swinburne University in Victoria and Liverpool Hospital in South Western Sydney. Monash Health invited patients to the study on 31 August 2020 via email, text and a poster in the waiting room; Swinburne University published the study and link to the questionnaire on the CCA website in the Swinburne Research Bulletin on 8 September 2020; and Liverpool Hospital invited patients to the study via email and a poster in its Gastroenterology waiting room. Ethics approval was not required by Monash Health. South Western Sydney Local Health District ethics approval was received on 17 September 2020.

The survey included the full Health Literacy Questionnaire (HLQ) and one scale from the eHealth Literacy Questionnaire (eHLQ) to identify people's health literacy strengths and challenges:

1. HLQ Scale 1 – Feeling understood and supported by healthcare providers
2. HLQ Scale 2 – Having sufficient information to manage my health
3. HLQ Scale 3 – Actively managing my health
4. HLQ Scale 4 – Social support for health
5. HLQ Scale 5 – Appraisal of health information
6. HLQ Scale 6 – Ability to actively engage with healthcare providers
7. HLQ Scale 7 – Navigating the healthcare system
8. HLQ Scale 8 - Ability to find health information
9. HLQ Scale 9 – Understand health information well enough to know what to do
10. eHLQ Scale 5 – Motivated to engage with digital services

Also included in the survey were IBD knowledge and demographic questions.

Of the 1,313 online and 48 paper surveys collected, 868 surveys from people with IBD and 85 surveys from carers were retained for data analysis. Descriptive analysis was conducted to determine health literacy and demographic information about the survey participants and cluster analysis revealed a range of health literacy profiles within that population. Interviews with people with IBD and carers provided narratives about living with and managing IBD, which supported the development of the vignettes for use in the ideas generation workshops.

Progress Report 1 (see Appendix 1 of this Final Report) was submitted by the CGHE team to CCA on 16 December 2020 and provides a full description of the data analysis and findings from the first survey.

During Phase 1, the CGHE team led the development of a manuscript describing the study protocol. The manuscript was submitted on 21 September 2020 and published in BMJ Open on 7 August 2021 and can be found here: http://dx.doi.org/10.1136/bmjopen-2020-045059

The CGHE team conducted the analyses of all data. See Table 1 in Progress Report 1 for a full description of the participant demographics. In summary, 63.5% of participants living with IBD were female and the average age was 49.3 years (SD, standard deviation=17.2) with 9.2% aged 15-25 years. They were mainly Australian born (81.9%) and most spoke English at home (96.6%). About a quarter of them (26.7%) lived in regional or remote areas. Based on the Manitoba Index, a single item indicator of disease activity over an extended period of time (from constantly to occasionally active), 56.5% were classified as having active disease. For carers, the average age was 51.6 (SD=11.5), with 82.4% being female, all spoke English at home and 27.1% resided in regional or remote areas.

The cluster analysis for persons with IBD identified 13 clusters with different patterns of health literacy strengths and challenges. The cluster analysis for the carers of people with IBD identified 12 clusters of different health literacy patterns. To develop the vignettes, each of the cluster profiles was combined with its associated demographics and with information about people's lived experiences gained through narratives from interviews with 13 people with IBD and 4 carers. The resulting 8 vignettes were used in 9 ideas generation workshops and 2 online activities with 76 people (38 people with IBD and 38 healthcare professionals) across Australia (6 states and 1 territory). The workshops and online activities facilitated in-depth discussions with people with IBD, carers, and healthcare professionals about the health and self-management challenges faced by people with IBD and to enable the generation of ideas about what could be done to improve access to IBD information and services to support self-management of IBD.

The CGHE team led the workshops on Zoom during COVID-19 restrictions. The workshops were recorded with the consent of the participants and notes were taken during the workshops. These workshop data were collated, coded and analysed by the CGHE team, and resulted in 70 ideas within 6 themes:

1. Communicate in effective ways and understand the needs and perspectives of community members
2. Make access to services, information and technology easy
3. Support community connections, social networks, and mental health care
4. Develop, make accessible and distribute information and resources
5. Raise public awareness of CCA and knowledge about IBD
6. Advocate for policy at government level

Ethics for Phase 2 was approved on 19 May 2021.

Progress Report 2 (see Appendix 2) was submitted by the CGHE team to CCA on 2 June 2021 and provides a full account of the vignettes, ideas and themes resulting from Phase 1.

Ophelia Phase 2

In the second phase of the Ophelia process, the CGHE team facilitated meetings and discussions with CCA and the Project Advisory Group about how they will rate and prioritise the action ideas according to internal CCA activities, policies, existing projects, and strategic priorities. Comprehensive and in-depth processes to integrate the workshop ideas into the organisational structure resulted in CCA identifying actions that they were already doing; actions that could be implemented in the short term; actions that could be considered for implementation in other existing CCA projects; and actions that could be implemented in the future with, for example, further resources. The CCA team developed a detailed program logic to align actions with organisational strategies and to guide the implementation of the actions, the mechanism of which was decided to be the upgrading of the CCA website and development of resources based on the ideas generated through the Ophelia process.

Conference presentations

During this second phase, the CGHE team had abstracts accepted for presentations about the CCA cluster analysis and the health literacy actions arising from the workshops to two 2021 virtual conferences:

- A poster at the International Society for Quality of Life Research (ISOQOL) conference: *From patient-centred measures to patient-centred interventions: Capturing the heterogeneity of patient groups to inform intervention development*
- An oral presentation at the Global Health Literacy Summit: *Health literacy actions – perspectives from people living with inflammatory bowel disease (IBD)/carers and health professionals*

Ophelia Phase 3

On 9 of March 2022, CCA launched its new website with updated and new resources. The new website housed resources that responded to the IBD information and service needs identified in Phase 1 of the project. The updated and new resources included health information topics about:

- Crohn’s disease, including symptoms, diagnosis and treatment
- ulcerative colitis, including symptoms, diagnosis and treatment
- other types of IBD, including IBD unclassified and microscopic colitis
- nutrition
- travel
- fertility and pregnancy
- sexuality
- psychological health
- fatigue

- medications, including adalimumab, aminosalicylates, corticosteroids, golimumab, infliximab, methotrexate, thiopurines, tofacitinib, ustekinumab and vedolizumab
- complementary and alternative medicine
- surgery
- complications with IBD and other conditions connected to IBD
- remission

Also launched through this project was an IBD Service Locator to help people find an IBD health service near them and the Connect with a Peer confidential service to provide support for people with IBD, their families and friends.

CCA assisted the Gastroenterological Society of Australia (GESA) with a review of 18 consumer information materials on topics including medication, vaccinations, nutrition and travel that were published online in December 2021. GESA approved these resources being published on the CCA website. Coordination of these resources has avoided duplication of high-quality education produced through this project.

Ethics for Phase 3, the evaluation of the website resources using a survey (Survey 2), was approved on 24 June 2022.

Survey 2

The CGHE team prepared Survey 2 in Qualtrics and sent CCA a link to host on their website. The link to the survey was set to "pop up" on the CCA website after a user had been on a page for 2 minutes. CCA also promoted the survey through its social media channels. Participants of the first survey who had consented to being contacted about further research were emailed the link and invited to complete the survey. Survey 2 was conducted only online.

The introduction to the survey asked potential participants to first visit the CCA website and view some of the resources before completing the survey. The survey consisted of 8 HLQ scales (Scale 4 'Social support for health' was excluded because no change was expected), eHLQ Scale 5 Motivated to engage with digital health services, and two scales from the Health Education Impact Questionnaire (heiQ) including Scale 1 'Health-directed activities' and Scale 6 'Understanding of health concepts and language'. Also included were the IBD knowledge and demographic questions. To elicit feedback about the CCA website and resources, 8 statements of strongly disagree to strongly agree were included:

1. I intend to tell other people that this website is useful
2. The CCA website contains information that will help me to manage my health
3. I trust the information and advice on this website
4. The information and resources on this website are well organised
5. I feel it was worth my time and effort to spend time looking at the information on this website
6. Difficult topics about IBD are handled well in the resources on this website
7. The website content is relevant to my situation
8. The perspectives of people with IBD are represented well on this website

There were also free text options for participants to provide feedback.

Recruitment for Survey 2 was conducted from 2 September to 15 November 2022. Surveys were received from 230 participants, of which 148 surveys were retained for data analysis. Demographic characteristics of Survey 2 participants were similar to Survey 1 participants except they were a little older with only 2.76% of participants who were aged from 15-25. The survey results indicated that, overall, participants felt the website information was from reliable and trusted sources and that it directed them to appropriate IBD and other relevant services.

Progress Report 3 (see Appendix 3) was submitted to CCA on 20 January 2023 and provides a full description of the data analysis and findings. This was the final progress report submitted by the CGHE team to CCA. The rest of this Final Report describes the activities and findings of the final evaluation of CCA website resources.

A project extension request was submitted to ethics by the CGHE team to extend the project end date from 29 June 2023 to 30 September 2023. This request was approved on 18 May 2023.

Survey 3

Following the launch of the new website, CCA continued to source and develop new resources. The new resources were uploaded to the CCA website in the first few months of 2023. These resources included:

- information targeted at kids, teens and parents
- information about differentiating between IBD and IBS
- more detailed information about nutrition:
    - optimising bone health in IBD
    - anaemia in IBD
    - exclusive enteral nutrition for Crohn's disease
    - managing a high output stoma in IBD
    - frequently asked dietary questions in IBD
    - eating well when feeling unwell with IBD
- three educational support videos:
    - managing my Crohn’s disease or ulcerative colitis
    - working with someone who has Crohn’s disease or ulcerative colitis
    - my school friend has Crohn’s disease or ulcerative colitis
- financial information and services to help reduce costs living with IBD
- information and support for people living in rural and remote locations
- information about supporting someone with IBD and communicating about my IBD
- QR code poster to help clinicians link their patients to CCA information and services
- information about IBD translated in languages other than English:
    - Arabic
    - Farsi
    - Punjabi
    - Simplified Chinese
    - Vietnamese

CCA assisted the Dietitian Crohn's Colitis Australian Network (DECCAN) with review of 8 consumer information materials on nutrition related topics that were published online in 2023. DECCAN approved these resources being published on the CCA website. Coordination of these resources has avoided duplication of high-quality education produced through this project.

CCA collaborated with Ethnolink to develop culturally appropriate information. The information was translated by a NAATI certified translator and reviewed by a second NAATI certified translator.

Survey 3 was conducted from 22 July to 30 August 2023 as a follow up evaluation of the updated website resources. Survey 3 was a repeat of Survey 2 so that data comparisons could be made. The CGHE team provided a survey link to CCA for the website pop up. Email invitations were again sent to participants who had consented to taking part in further research in Surveys 1 and 2, and CCA again promoted the survey through its social media channels, with the survey being undertaken only online.

A total of 239 people responded to Survey 3, with 66 responses excluded because the eligibility criteria were not met or participants did not provide consent. Out of the 173 surveys retained for analysis, 119 participants provided complete responses to questions about demographics, health literacy, and self-management and were included in the health literacy analysis.

Participant characteristics

Survey 3 participants were mainly persons living with IBD (92.5%) with only 5.8% being carers. Close to half (45.6%) had visited the updated website for the first time on the day of completing the survey and 42.2% had visited the website 2 to 5 times. Table 2 presents the general characteristics of the 173 participants.

Table 2. Characteristics of Survey 3 participants (N=173)

Characteristics	**n (%)**
Status	
Persons living with IBD	160 (92.5)
Carers[a]	10 (5.8)
Health professionals[b]	4 (2.3)
Other or prefer not to say	4 (2.3)
Times visited new CCA website since March 2023	
For the first time today	79 (45.6)
2-5 times	73 (42.2)
6-10 times	11 (6.4)
More than 10 times	10 (5.8)

[a] One carer also identified as person living with IBD

[b] Four health professionals also identified as persons living with IBD

For the 160 participants living with IBD, the average number of years since diagnosis was 15.2 years and 53.8% of them had a diagnosis of 10 or more years. According to the Manitoba Index of constantly to occasionally active disease, 70.7% had active disease. (Table 3).

Table 3. IBD characteristics of participants living with IBD (N=160)

Characteristics	n (%)
Average years of living with IBD (Mean, SD, Range: 0-57)	15.2 (14.1)
Number of years living with IBD	
Less than 1 year	19 (11.9)
1-4 years	29 (18.1)
5-9 years	24 (15.0)
10 or more years	86 (53.8)
Manitoba Index (past 3 months symptoms)	
Constantly active	44 (27.5)
Often active	15 (9.4)
Sometimes active	34 (21.3)
Occasionally active	20 (12.5)
Rarely active	21 (13.1)
Was well in the past 3 months	26 (16.3)

The average age of participants who provided complete data (n=119) is 52.1 years and only 5.9% of these people were aged 15-25 years. Close to half (47.1%) were aged 56 years or older. Similar to the previous two surveys, the majority of participants were female (71.4%). While 23.5% of participants were born overseas, 95.8% of them spoke English at home. People with university or above education made up 45.4% of the survey sample, 32.8% were working full time, and 70.6% lived in major cities. See Table 4.

Table 4. Demographic characteristics of Survey 3 participants who provided complete data (N=119)

Characteristics	n (%)
Status	
Persons living with IBD	114 (95.8)
Carers (1 carer also person living with IBD)	6 (5.0)
Health professionals (also persons living with IBD)	3 (2.5)
Age (mean, SD, range: 16-83)	52.4 (16.5)
Age	
15-25 years old	7 (5.9)
26-40 years old	22 (18.5)
41-55 years old	33 (27.7)
56-70 years old	40 (33.6)
71 years old or above	16 (13.5)
Gender	
Female	85 (71.4)
Male	34 (28.6)
Country born	
Australia	91 (76.5)
Other	28 (23.5)
English as main language	114 (95.8)
Aboriginal or Torres Strait Islander	1 (0.8)
Number of household members (mean, SD, range:1-6)	2.65 (1.2)
Number of household members	
Lived alone	16 (13.4)
2 people	54 (45.4)
3-4 people	38 (31.9)
5 or more people	11 (9.3)

Characteristics	**n (%)**
Education completed	
Primary school or less	3 (2.5)
High school	31 (26.1)
Trade certificate/TAFE/Diploma	31 (26.1)
University undergraduate degree	31 (26.1)
University postgraduate degree	23 (19.3)
Employment	
Full time	39 (32.8)
Part time	21 (17.6)
Not working	7 (5.9)
Home duties	4 (3.4)
Student	6 (5.0)
Retired	33 (27.7)
Other	8 (6.7)
Residence	
Major city	84 (70.6)
Inner regional	25 (21.0)
Outer regional	8 (6.7)
Remote or very remote	1 (0.8)
Long-standing health condition(s)	
None	3 (2.5)
Crohn’s disease	67 (56.3)
Ulcerative colitis	46 (38.7)
Indeterminate colitis	4 (3.4)
Arthritis or joint problems	39 (32.8)
Lung or breathing problems	18 (15.1)
Back pain	24 (20.2)
Cancer	4 (3.4)
Kidney problems	6 (5.0)
Heart problem	11 (9.2)
Diabetes	4 (3.4)
Anxiety	34 (28.6)
Depression	18 (15.1)
Other	22 (18.5)
Number of long-standing health condition (mean, SD, range: 0-8)	2.53 (1.7)
Total number of long-standing health condition per person	
One	40 (33.6)
Two	26 (21.8)
Three	17 (14.3)
Four	14 (1.8)
Five	10 (8.4)
Six or more	8 (6.7)

Website experiences and feedback – Survey 3

The 8 website feedback statements used in Survey 2 were also used in Survey 3. Similar to the results of Survey 2, the majority of participants agreed or strongly agreed to all 8 statements (Table 5). However, it is worth noting that 10.5% of the participants (n=16) disagreed with the statement ‘The website content is relevant to my situation’, with comments such as there is a ‘…focus on youth and newly diagnosed’ and the ‘…website seems mainly interested in young people with IBD…’. Of these 16 participants, 15 were people living with IBD and 1 was a carer. Most (n=12) were 41 years or older, 11 had been diagnosed for 10 or more years, and 10 reported constantly active, often active and sometimes active symptoms in the past 3 months. Also interesting, is that these 16 participants said they did not make changes in response to the question asking about any changes people made after reading information on the CCA website.

Table 5. Website feedback (N=152)

Statements	**Strongly disagree n (%)**	**Disagree n (%)**	**Agree n (%)**	**Strongly agree n (%)**
1. I intend to tell other people that this website is useful	2 (1.3)	11 (7.2)	98 (64.5)	41 (27.0)
2. The CCA website contains information that will help me to manage my health	2 (1.3)	6 (3.9)	108 (71.1)	34 (22.4)
3. I trust the information and advice on this website	2 (1.3)	2 (1.3)	76 (50.0)	70 (46.1)
4. The information and resources on this website are well organised	3 (2.0)	4 (2.6)	104 (68.4)	40 (26.3)
5. I feel it was worth my time and effort to spend time looking at the information on this website	2 (1.3)	4 (2.6)	98 (64.5)	47 (30.9)
6. Difficult topics about IBD are handled well in the resources on this website	2 (1.3)	6 (3.9)	108 (71.1)	35 (23.0)
7. The website content is relevant to my situation	1 (0.7)	16 (10.5)	101 (66.4)	32 (21.1)
8. The perspectives of people with IBD are represented well on this website	1 (0.7)	9 (5.9)	98 (64.5)	43 (28.3)

When participants were asked if they made changes after viewing information on the CCA website, 65.8% indicated that they made changes in their approach to living with IBD (Table 6). These included changes to diet (29.6%), communicating with friends and family (22.4%), and sleep or rest (17.8%). In fact, many of these participants made more than one change, 11.8% made 3 changes and 14.5% of participants made 4 to 10 changes, including one participant who reported 10 changes. However, about one third (34.2%) did not make any changes. Among these 34.2% of participants, a few indicated that it was only the first time they visited the website and some indicated that they were in remission and no change was needed.

Table 6. Changes made after viewing Crohn's & Colitis Australia website (N=152)

Changed approach to:	**n (%)**
Diet	45 (29.6)
The health system or health professionals	20 (13.2)
Medication or treatment	23 (15.1)
Psychological health	17 (11.2)
Work	15 (9.9)
Education	11 (7.2)
Communicating with friends or family	34 (22.4)

Changed approach to:	n (%)
Physical activity	22 (14.5)
Social activities	9 (5.9)
Travel	8 (5.3)
Sleep or rest	27 (17.8)
Other[a]	2 (1.3)
Number of approach(es) changed:	
Changed 1 approach	20 (13.2)
Changed 2 approaches	21 (13.8)
Changed 3 approaches	18 (11.8)
Changed 4-10 approaches	22 (14.5)
Did not make any changes	52 (34.2)

[a]Other – responses were how to research information and reach out to people living with IBD

Website analytics show that the most frequently accessed health information between 9 March 2022 and 30 August 2023 on the CCA website were topics that helped people to learn about Crohn's and colitis (including symptoms, diagnosis and treatment), as well as resources about nutrition and information about Crohn's and colitis for employers (Table 7). See Appendix 4 for new website analytical data.

Table 7. Most frequently accessed Crohn's & Colitis Australia webpages with health information

Most frequently accessed webpages	Total page views
Crohn's Disease Symptoms	20,843
Nutrition	17,895
Crohn's Disease Treatment	11,217
Ulcerative Colitis Symptoms	9,618
About Crohn's Disease	8,986
Crohn's Disease Diagnosis	8,618
Ulcerative Colitis Treatment	6,662
About Ulcerative Colitis	4,715
Working with IBD – Guide for Employers	3,018
Ulcerative Colitis Diagnosis	2,953

In the free text section about actions taken after reading information on the CCA website, 52 people commented about actions taken in relation to diet, mental health, communicating with health professionals, and managing medication and treatment, among other actions including communicating with friends and family, improving physical activity and sleep or rest, with only a few people commenting about actions to do with work or other areas of life.

One person commented that they had booked in to talk to the nurse, called the help line, communicated more often with their doctor, and taken control of their treatment. Another person explained how they had been able to communicate with their family about the types of foods they can eat, with another person saying they had consulted a nutritionist to put a plan together for better management of their diet. Others talked about keeping a food diary, moderating their diet when they get a flare up, and eating or eliminating certain foods. Some said they now better understand or are complying to the medication they take and others have sought the help of specialists: 'I have sought out a gastro and am now involved with a dietitian I found on this website'.

Several people commented that their awareness of their condition and symptoms had increased by reading the information on the CCA website, with others saying that they were now accepting they were living with their condition for life. Some people said they had sought support through peers: 'I used the Peer Support Network to reach out to a peer with UC when I was in hospital a month ago and knowing someone was out there who went through a very similar situation made me feel less alone'. Some people communicated more with friends: 'I have opened up to more of my friends about my Crohn's and it has made me feel a lot better'. Comments from other people were that they had joined the monthly support group, had talked about their condition with some people and this made it less embarrassing, and that it was good for their mental health to have access to the CCA information.

A person who commented about action they took at work said: 'I have been able to speak to my employer about the impacts of IBD and share appropriate resources to back up my claim / request for flexible working arrangements…'. This person explains that they have been able to move to a part time role instead of full time. Others talked about making time for mindfulness, taking their psychological wellbeing seriously, monitoring their fatigue and finding coping mechanisms, and understanding the important of sleep and rest, with some mentioning specific actions such as having a regular bedtime.

Health literacy, digital health literacy and self-management – Survey 3

Similar to Survey 2, the results for Survey 3 (Table 8) showed that HLQ Scale 1 'Feeling understood and supported by healthcare professionals' had the highest mean score (M=3.30, SD=0.60) among the four HLQ Part 1 scales with a score range of 1 to 4 (1=strongly disagree, 4 = strongly agree). Among the four HLQ Part 2 scales with a score range of 1 to 5 (1=Cannot do or Always difficult, 5=Always easy), HLQ Scale 9 'Understand health information well enough to know what to do' had the highest mean score (M=4.12, SD=0.57). The scores of the eHLQ scale and the two heiQ scales were similar to the results of Survey 2.

Table 8. HLQ, eHLQ and heiQ scale scores (N=118)*

Scale	Mean (SD) [95% CI]
Health Literacy Questionnaire (HLQ)	
	Score range: 1 (strongly disagree) – 4 (strongly agree)
1. Feeling understood and supported by healthcare professionals	3.30 (0.60) [3.19-3.41]
2. Having sufficient information to manage my health	2.84 (0.56) [2.74-2.94]
3. Actively managing my health	3.10 (0.47) [3.02-3.19]
5. Appraisal of health information	3.05 (0.45) [2.97-3.13]
	Score range: 1 (cannot do or always difficult) – 5 (always easy)
6. Ability to actively engage with healthcare professionals	3.85 (0.76) [3.71-3.99]
7. Navigating the healthcare system	3.54 (0.71) [3.42-3.67]
8. Ability to find good health information	3.90 (0.61) [3.79-4.01]
9. Understand health information well enough to know what to do	4.12 (0.57) [4.02-4.22]
	Score range: 1 (strongly disagree) – 4 (strongly agree)
eHealth Literacy Questionnaire (eHLQ)	
5. Motivated to engage with digital services	2.91 (0.56) [2.81-3.02]
Health Education Impact Questionnaire (heiQ)	
1. Health-directed activities	3.01 (0.74) [2.87-3.14]

6. Understanding of health concepts and language	2.83 (0.56) [2.73-2.93]

*One participant excluded due to missing value for HLQ Scale 5 Appraisal of health information.

Survey 2 and Survey 3 results comparison

Participant characteristics – Surveys 2 and 3

From the 119 Survey 3 participants who provided complete responses, 32 were identified as having also completed Survey 2. All were persons living with IBD. Importantly, the overall demographic characteristics were quite similar to the full sample of Survey 3 (Table 9).

Table 9. Demographic characteristics of participants who completed Survey 2 and Survey 3 (N=32)

Characteristics	**n***
Status	
Persons living with IBD	32
Health professionals (also person living with IBD)	1
Average years of living with IBD (Mean, SD, Range: 1-47)	18.5 (12.6)
Manitoba Index (past 3 months symptoms)	
Constantly active	5
Often active	11
Sometimes active	3
Occasionally active	5
Rarely active	4
Was well in the past 3 months	5
Age (mean, SD, range: 21-76)	53.1 (15.7)
Gender	
Female	20
Male	12
Born in Australia	28
English as main language	32
Education	
Primary school	1
High school	5
Trade certificate/TAFE/Diploma	7
University undergraduate degree	13
University postgraduate degree	6
Employment	
Full time	8
Part time	11
Not working	1
Home duties	2
Student	1
Retired	6
Other	3
Residence	
Major city	27
Inner regional	4
Outer regional	1
Long-standing health condition	
Crohn’s disease	17
Ulcerative colitis	14
Indeterminate colitis	1

Characteristics	n*
Arthritis or joint problems	11
Lung or breathing problems	3
Back pain	10
Kidney problems	3
Diabetes	1
Anxiety	6
Depression	3
Other	8

*% not reported due to sample size smaller than 100.

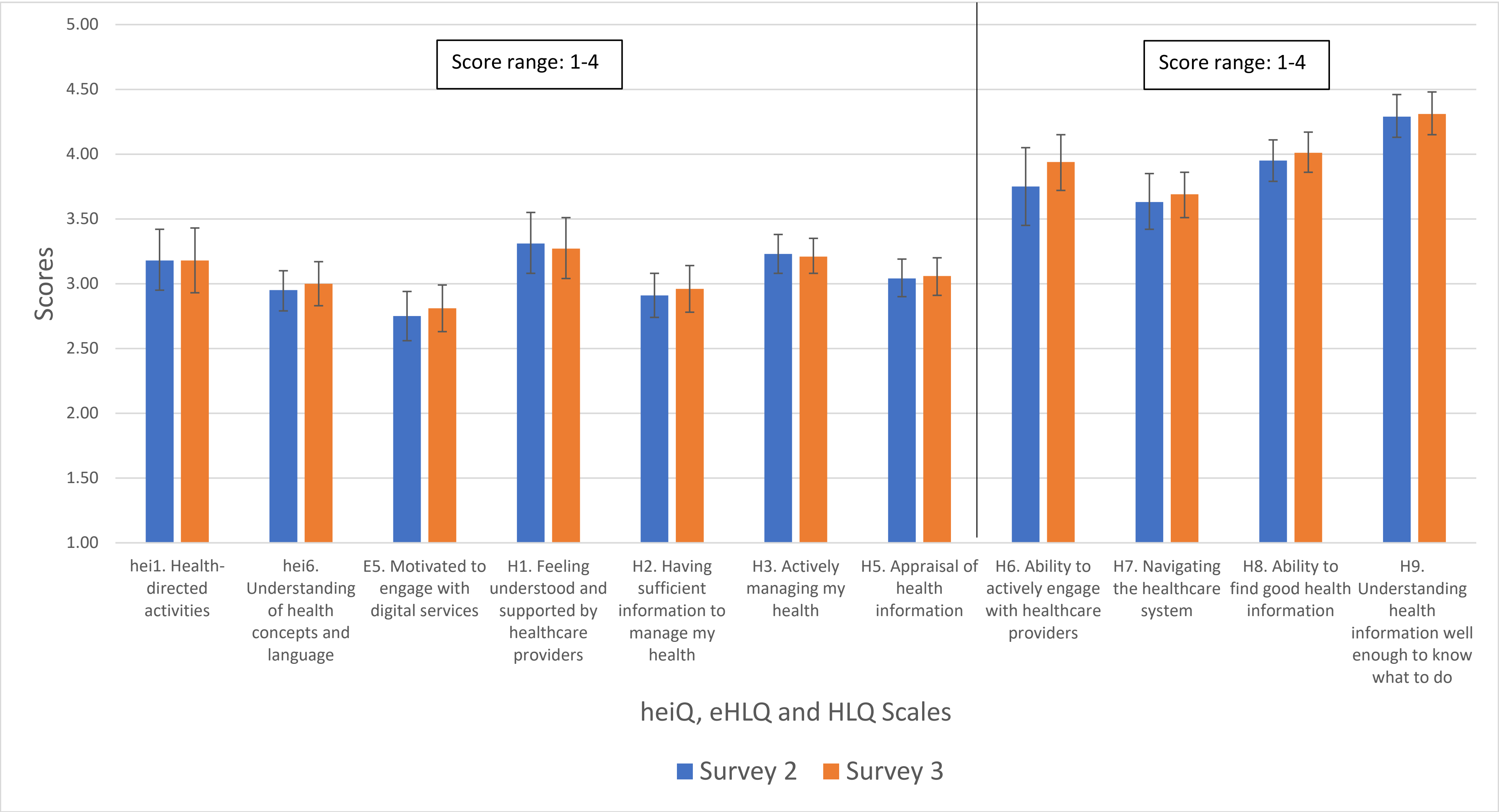
Health literacy, digital health literacy and self-management scores – Surveys 2 and 3

A paired-sample t-test was conducted and no significant differences between scores were found although a slight increase was noted in HLQ Scale 6 'Ability to actively engage with healthcare professionals' scores from Survey 2 (M=3.75, SD=0.84) to Survey 3 (M=3.94, SD=04.0) (Table 10) and Figure 2).

Table 10. Survey 2 and Survey 3 health literacy, digital health literacy and self-management scores (N=32)

	Mean (SD) [95% CI]	
Scale	**Survey 2**	**Survey 3**
Health Literacy Questionnaire (HLQ)		
	Score range: 1 (strongly disagree) – 4 (strongly agree)	
1. Feeling understood and supported by healthcare professionals	3.31 (0.64) [3.07-3.54]	3.27 (0.65) [3.03-3.50]
2. Having sufficient information to manage my health	2.91 (0.47) [2.74-3.08]	2.96 (0.49) [2.78-3.14]
3. Actively managing my health	3.23 (0.41) [3.08-3.38]	3.21 (0.38) [3.07-3.34]
5. Appraisal of health information	3.04 (0.40) [2.89-3.18]	3.06 (0.40) [2.92-3.21]
	Score range: 1 (cannot do or always difficult) – 5 (always easy)	
6. Ability to actively engage with healthcare professionals	3.75 (0.84) [3.45-4.05]	3.94 (0.59) [3.73-4.16]
7. Navigating the healthcare system	3.63 (0.60) [3.41-3.84]	3.69 (0.48) [3.52-3.87]
8. Ability to find good health information	3.95 (0.45) [3.79-4.11]	4.01 (0.44) [3.85-4.16]
9. Understand health information well enough to know what to do	4.29 (0.46) [4.12-4.45]	4.31 (0.45) [4.14-4.47]
	Score range: 1 (strongly disagree) – 4 (strongly agree)	
eHealth Literacy Questionnaire (eHLQ)		
5. Motivated to engage with digital services	2.75 (0.53) [2.56-2.94]	2.81 (0.50) [2.63-2.99]
Health Education Impact Questionnaire (heiQ)		
1. Health-directed activities	3.18 (0.64) [2.94-3.41]	3.18 (0.69) [2.93-3.43]
6. Understanding of health concepts and language	2.95 (0.43) [2.80-3.11]	3.00 (0.46) [2.83-3.17]

Figure 2. Survey 2 and Survey 3 health literacy, digital health literacy and self-management scores (N=32)



Website feedback – Surveys 2 and 3

Table 10 displays the changes in the responses to the 8 website feedback statements. Survey 3 clearly has more participants who strongly agreed to all 8 statements (Figure 3). The increase in the number of people who strongly agreed is especially apparent for the statements ‘I feel it was worth my time and effort to spend time looking at the information on this website’ (25.0% in Survey 2 to 43.8% in Survey 3) and ‘Difficult topics about IBD are handled well in the resources on this website’ (18.8% in Survey 2 to 40.6% in Survey 3).

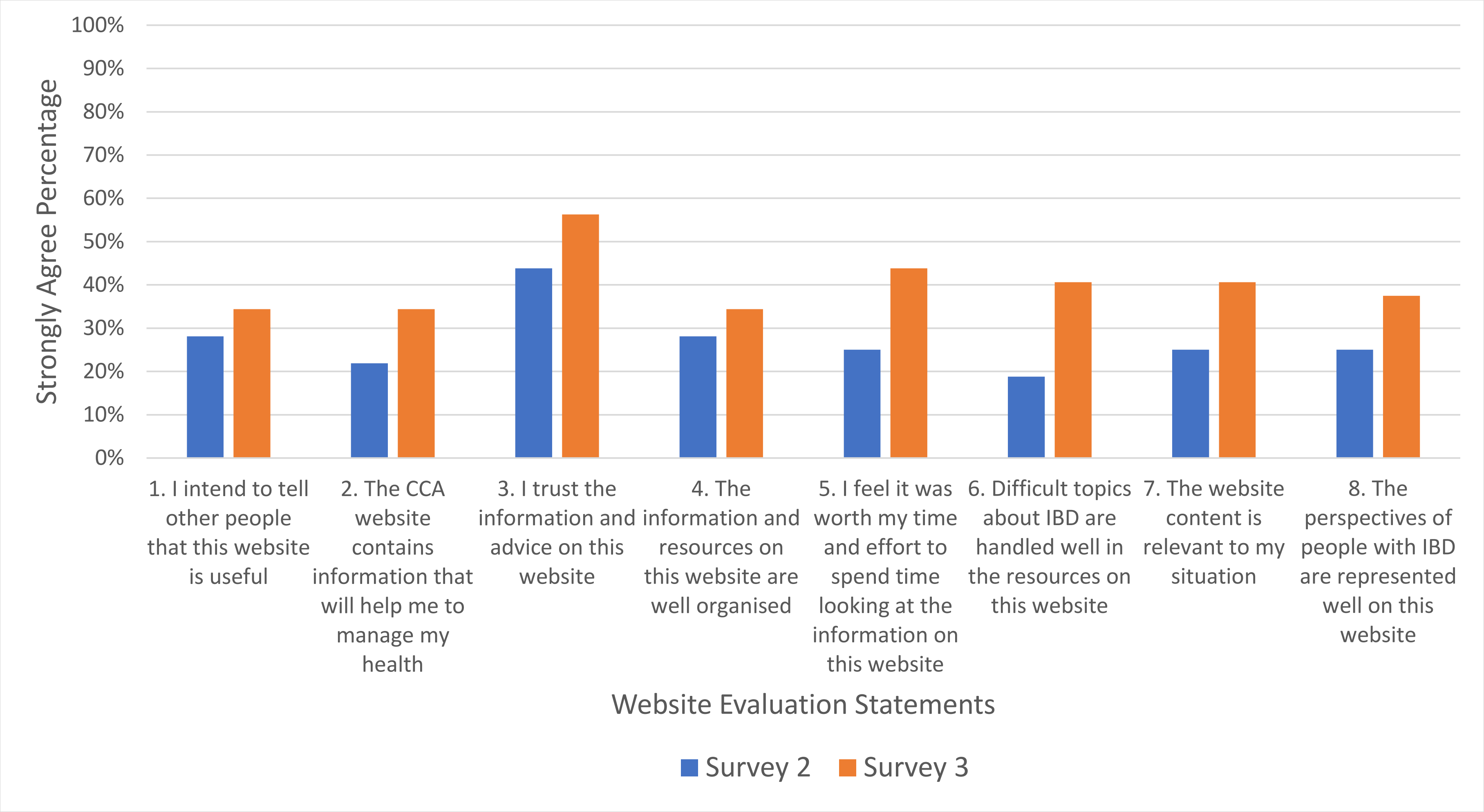
See also Appendix 5: Survey 1 and Survey 3 score comparisons.

Table 11. Website feedback from Survey 2 and Survey 3 (N=32)

				Survey 2				**Survey 3**
Statements	**Strongly Disagree n (%)**	**Disagree n (%)**	**Agree n (%)**	**Strongly agree n (%)**	**Strongly Disagree n (%)**	**Disagree n (%)**	**Agree n (%)**	**Strongly agree n (%)**
1. I intend to tell other people that this website is useful	0	4 (12.5)	19 (59.4)	9 (28.1)	1 (3.1)	3 (9.4)	17 (53.1)	11 (34.4)
2. The CCA website contains information that will help me to manage my health	0	1 (3.1)	24 (75.0)	7 (21.9)	1 (3.1)	2 (6.3)	18 (56.3)	11 (34.4)
3. I trust the information and advice on this website	0	1 (3.1)	17 (53.1)	14 (43.8)	1 (3.1)	0	13 (40.6)	18 (56.3)
4. The information and resources on this website are well organised	0	1 (3.1)	21 (65.6)	9 (28.1)	1 (3.1)	1 (3.1)	19 (59.4)	11 (34.4)
5. I feel it was worth my time and effort to spend time looking at the information on this website	0	0	24 (75.0)	8 (25.0)	1 (3.1)	1 (3.1)	16 (50.0)	14 (43.8)
6. Difficult topics about IBD are handled well in the resources on this website	0	0	24 (75.0)	6 (18.8)	1 (3.1)	1 (3.1)	17 (53.1)	13 (40.6)
7. The website content is relevant to my situation	0	3 (9.4)	20 (62.5)	8 (25.0)	0	4 (12.5)	15 (46.9)	13 (40.6)
8. The perspectives of people with IBD are represented well on this website	0	2 (6.3)	21 (65.6)	8 (25.0)	0	3 (9.4)	17 (53.1)	12 (37.5)

Note: % reported for easy comparison between the two surveys.

Figure 3. Comparison of Survey 2 and Survey 3 participants answered Strongly Agree to website evaluation statements



Website information evaluation

To evaluate the materials on the new website, CCA implemented Patient Education Materials Assessment Tool (PEMAT). The PEMAT is a systematic method designed to evaluate and compare the understandability and actionability of patient or consumer education materials. There are two versions of the PEMAT:

1. PEMAT-P for printable materials (e.g., brochures, pamphlets, PDFs), consisting of 17 items measuring understandability and 7 items measuring actionability.
2. PEMAT-A/V for audiovisual materials (e.g., videos, multimedia materials), consisting of 13 items measuring understandability and 4 items measuring actionability.

The PEMAT was used to evaluate three health information resources on the previous CCA website compared with new health information that launched 9 March 2022 (Table 12 and Appendix 6).

Table 12. Crohn's & Colitis Australia website PEMAT scores

Resource	Old website rating	New website rating
About Crohn's Disease	Understandability: 80% Actionability: 0%	Understandability: 100% Actionability: 40%
Travel and IBD	Understandability: 80% Actionability: 0%	Understandability: 92% Actionability: 60%
Working with IBD	Understandability: 87% Actionability: 60%	Understandability: 92% Actionability: 100%

The new CCA website, launched on 9 March 2022, aimed to provide more comprehensive, evidence-based IBD resources and improved website navigation than the previous website. Table 13 outlines key differences between the previous and new CCA websites to explain the variability in PEMAT scores.

Table 13. PEMAT scores of the previous and new Crohn's & Colitis Australia websites

Previous website	New website
Website menu has limited navigation features and minimal health information landing pages.	Hamburger menu for improved navigation and topics presented in a logical order. Homepage includes navigation bar to efficiently direct users to specific content.
Webpages have limited function for interaction.	Improved functionality to allow interaction; for example, IBD Service Locator map and Support Groups map.
Evidence-based information locked through a login on a separate website (CC Hub).	All information freely accessible on one website.
Many topics presented on each health information webpage. However, limited detail is provided on each topic. Material can contain content distracting from the purpose.	One topic presented per webpage and more detail is presented on each topic. Material does not contain information distracting from the purpose.
No summary presented at the top of each	Key points presented at the top of each health

health information webpage.	information webpage.
Limited actionable information.	Action driven health information in manageable, explicit steps.
Health information is provided as: • webpage information • PDF downloads • print materials	Information provided in a variety of formats, including: • webpage information • PDF downloads • print materials • tip sheets • animation videos
Health information in English only.	Health information in English, Arabic, Farsi, Punjabi, Simplified Chinese, and Vietnamese.
Health information not targeted at priority population groups.	Health information specifically targeted at: • young people • people living in rural and remote locations • carers, friends and family of people living with IBD
Some webpages publish personal stories only, rather than evidence-based information.	Whilst personal stories are on the website, the website includes more topics with evidence-based information.
Limited visual aids utilised.	Visual aids to improve understandability.

Discussion

The evaluation of the CCA website clearly indicates that people living with IBD are finding the website resources useful to support them to self-manage their health and wellbeing. About two thirds of people reported that they are changing their behaviours, with some people describing specific self-management actions they are taking after reading information on the CCA website. It is particularly important to note that many people reported that they had changed their health behaviours in multiple ways. Notably, most users consider the website to be providing evidence-based recommendations related to diet, exercise, medication, mental health, communications, among other areas, and these resources are resonating with many of the website users.

Development of self-management behaviours

From these evaluation data, we can infer that many people living with IBD and accessing these resources will experience improvements in their health outcomes as a result of implementing evidence-base behaviours, as described within the sections of the website. Such behaviour change indicates that the health literacy of these respondents will change for the better. The fundamental elements of health literacy are being able to access, understand, appraise, remember, and use health information and services. The CCA website resources support these health literacy elements by providing evidence-based information in plain language and in multiple formats and languages, with health professional and service networks, peer support networks, community events, and other activities and information to complement and accompany many of the resources. The great majority of the evaluation survey participants have reported that they are more informed, have improved awareness of their health condition, and are taking action to self-manage their health, which indicates that health literacy and self-management have been developed as a result of people engaging with the CCA disease-specific website.

Website evaluation

Over 90% of respondents endorsed the website, meaning that they agreed or strongly agreed to the website evaluation statements about information quality in Surveys 2 and 3. Recruitment for the two evaluation surveys was through convenience sampling, with participants voluntarily completing a survey that was hosted as a pop-up on the CCA website. Sometimes this type of recruitment method can attract people who are unhappy with a service, but only 1 in 10 survey respondents, and sometimes 1 in 20, reported components of the website that they found were not satisfactory. One of the most important indicators of satisfaction is trust. Responses in Survey 3 to the statement 'I trust the information and advice on this website' indicates that only about 1 in 40 people had some doubts about the trustworthiness of the website information. Responses from people who completed both Surveys 2 and 3 shows a clear increase in the number of people strongly agreeing to the website evaluation statements. It is usually easy to answer 'agree' to a statement but to 'strongly agree' is a strong endorsement.

The lowest scoring statement ('The website content is relevant to my situation') is related to individuals' personal circumstances, which can be very specific to their own context. Some comments indicated that a couple of people had been looking for particular information for themselves or a family member. A few people felt that the perspectives of people with IBD could be better represented. Some people commented in the free text sections of Survey 3 that the needs of young people and people newly diagnosed seem to be over emphasised in the website resources, with some suggestions for more information about support for older people and about living with surgical outcomes. The focus on younger people is likely a result of this group of people being a specific target group for this research project because they have previously been a group of people being left behind, especially in situations such as the transition from paediatric to adult health services and care. While taking note that resources for older people on the website still need improvement, it is an important research outcome that the prominence of resources for younger people has been noticed.

Despite the increase in website resources for young people, Surveys 2 and 3 were under-represented by younger people and also men. This was noted in Survey 1 as well and, during the ideas generation workshops in Phase 1, a workshop was conducted specifically for young people with the aim of making sure their voice was heard. Two of the Ophelia vignettes for workshops (Nick and Emily) were created to depict the lives of young people (aged 15 to 25). Another vignette was about a 50-year-old woman, Li-ling, who had emigrated to Australia at 14 years old, and who had an 18-year-old daughter, Grace, both of whom had IBD. These vignettes incorporating the perspectives of young people, and carers, helped to generate ideas that subsequently informed the development of the resources for young people that were noticed in the evaluation surveys. Other important information to note about the survey data was that participants tended to be well educated and mainly lived in metropolitan areas. The interviews to inform vignettes that were conducted by the CGHE team specifically targeted a few people who lived in regional, rural and remote areas, and one vignette

(Mary) was created to depict an older woman who lived in a remote area that is a 7-hour drive from Perth. These efforts in the research process to make sure the data represented the diverse lives of people living with IBD, and the lives of their carers, was facilitated by the systematic Ophelia process and demonstrates the commitment of the CCA and CGHE teams to ensuring that the resources are appropriate, meaningful and useful to the people who seek information from the CCA website to support them in their experiences of managing IBD.

The generic, non-disease-specific Health Literacy Questionnaire (HLQ) did not detect any particular improvement in health literacy, which is not surprising because of the small sample size (N=32), and the content of the website is a passive self-directed educational experience. The small sample sizes means that the study may not have adequate power to detect a statistically significant difference between Surveys 2 and 3. Overall, across all scales, there was either no change, or some trends towards improvements. The largest improvement, although not statistically significant, was in HLQ Scale 6 'Ability to actively engage with healthcare providers', and with some of the free text comments about people now seeking specialists supported this change in score. Of note, is that the health literacy of the people surveyed is moderately high, although some people appear to not have sufficient information (HLQ Scale 2) but do report they understand health information well enough to know what to do (HLQ Scale 9). This may reflect the unavoidable complexity of IBD, the plethora of misinformation that is available, and how IBD can change over time for no apparent reason. It should be noted that people with higher health literacy challenges, and therefore higher capacity to benefit, are generally less likely to take part in surveys. It is therefore possible that many other people received substantial benefits but their information is not captured is this evaluation.

An important Survey 3 finding was that more people answered 'strongly agree' to all website feedback statements and 65.8% of participants reported that they changed their approach to living with IBD, indicating that the CCA website is already making impact into the lives of people living with IBD. With 10% of people indicating that the website is not relevant to their needs, it is important to continue with the development of resources to suit this older group of people who have been diagnosed for more than 10 years and who are still experiencing symptoms.

Overall, the website feedback indicates that the CCA website is highly organised, informative, and is clearly helping people to self-manage their health conditions and to improve their wellbeing. Only small opportunities for improvement were identified, including information for more diverse people and perhaps more stories to increase the sense that the many perspectives of people with IBD are being represented. Specifically, website resources for older people and people with more than 10 years of diagnosis are needed. Future research could target younger people and people from culturally diverse backgrounds because recruitment objectives for these groups were not met.

Appendices

The following appendices are attached to this report.

Appendix 1: Progress Report 1

Appendix 2: Progress Report 2

Appendix 3: Progress Report 3

Appendix 4: Google analytics new CCA website evaluation

Appendix 5: Survey 1 and Survey 3 score comparisons

Appendix 6: PEMAT Evaluation

Centre for Global Health and Equity

Crohn's & Colitis Australia

Ophelia Phase 1 – Progress Report (Consumer Education and Awareness of Inflammatory Bowel Disease project)

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16 December 2020

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Centre for Global Health and Equity
CCA Ophelia Progress Report

Introduction

This project seeks to support Crohn's & Colitis Australia (CCA), in partnership with their inflammatory bowel disease (IBD) stakeholder collaborators, to apply the Ophelia (Optimising Health Literacy and Access) process to facilitate improvements to self-management materials and interventions for people with inflammatory bowel disease (IBD). In particular, the project seeks to understand the health literacy needs of people experiencing vulnerabilities and who may not be accessing the health care they need to manage their IBD. The first phase of the Ophelia process involves assessing health literacy needs and strengths of people with IBD and their carers. The objectives of this first phase of the CCA Ophelia project are to:

- Identify the health literacy profiles of people in Australia who are living with IBD, and their carers; and
- Identify the factors influencing engagement with health information and health services, in particular to do with management of IBD.

The Centre for Global Health and Equity (CGHE) at Swinburne University of Technology was commissioned by CCA to provide research design, data analysis, statistical reporting and evaluation of the Consumer Education and Awareness of IBD (CEA-IBD) project. The CEA-IBD project is funded by an Australian Government Department of Health Public Health and Chronic Disease Program grant (GO2800). The Swinburne team started on the project in late March 2020. This is a report of the progress made towards implementing the key activities and deliverables in relation to the anticipated project timeline.

1. Key activities

1.1 Stakeholder engagement and ethics

Purpose: A critical element of successful health services improvement initiatives is to understand local contexts and genuinely engage with service users and stakeholders. With this deep understanding and engagement, fit-for-purpose solutions can be generated from local wisdom and the stakeholders responsible for implementation of the solutions have full ownership from inception. The Swinburne Ophelia team has worked closely with the CCA team and the CCA Project Advisory Committee and this is a critical part of the ongoing project activities.

Activities:

- Meetings between the Swinburne and CCA teams occur fortnightly.
- Swinburne team members attend the CCA Project Advisory Committee monthly meetings.
- A participant engagement planning meeting was held on Monday 27 April from 7 – 9pm: the purpose of this meeting was to identify groups of people who need access to better information and support for IBD, and to identify how to invite them to the project.
- Application to Swinburne University of Technology Human Research Ethics Committee (HREC) – ethics approved for Ophelia Phase 1 on 27 July 2020.
- Study protocol manuscript submitted to BMJ Open on 21 September 2020 (see Appendix 3).

Comments:

- Some minor delay to the project was experienced in the first half of 2020 due to disruptions from the COVID-19 pandemic but the project is now largely on track.
- Manuscript is under review.

1.2 Data collection

Purpose: The health literacy of people in Australia who are living with IBD and their carers was assessed and profiled. The main aim of the survey was to generate health literacy profiles of a wide range of people living with IBD and their carers, especially people who live in rural/remote areas and young people aged 15 – 25 years. These data will inform the vignettes for that are presented in the community ideas generation workshops.

Activities:

- Qualtrics online and paper questionnaires (for people with IBD and for carers) were developed and ready for launch by CCA on Monday 10 August 2020.
- Monash Health invited patients to the study on 31 August 2020 via email, text and a poster in the waiting room.
- Swinburne University of Technology published the study and link to the questionnaire on the CCA website in the Swinburne Research Bulletin on 8 September 2020.
- Liverpool Hospital in South Western Sydney invited patients to the study via email and a poster in waiting room on 22 September 2020.
- Recruitment closed on Friday 31 October 2020.

Comments:

- Recruitment occurred through promotion of the online questionnaire on the CCA website, the professional networks of CCA, and via paper versions mailed to CCA members who prefer to receive paper communications.
- Recruitment was also supported by Monash Health Gastroenterology and Monash Children's Hospital (Melbourne) and Liverpool Hospital Gastroenterology (South Western Sydney Local Health District), and by Swinburne University.
- Ethics not required by Monash Health for email/text/poster invitation to patients.
- South Western Sydney Local Health District ethics approval to email the link to patients and place a poster in the waiting room was received on 17/09/2020

1.3 Demographics, cluster analysis and vignette development

Purpose: The survey includes the Health Literacy Questionnaire (HLQ) and one scale from the eHealth Literacy Questionnaire (eHLQ). The survey results and the data gained from the interviews were analysed to identify key health literacy strengths and needs of community members.

Activities:

- Data from online and paper questionnaires were collated for persons living with IBD (n=868) and their carers (n=85).
- Descriptive and cluster analysis is complete.

- Interviews to inform vignette development is underway.
- Vignette development for ideas generation workshops will take place from December 2020 to early February 2021.

Comments:

- Full results are displayed in Section 3. Results to date.
- An example vignette is provided in section 3.5.

2. Next steps

2.1 Ideas generation workshops

Purpose: The ideas generation workshops will be held with health professionals, people with IBD, and carers of people with IBD. The data collected will be presented to workshop participants in the form of the vignettes, which are hypothetical case studies based on the data collected. The specific questions used to guide the workshops are: 1) Do you recognise this person / have clients like this in your community?; 2) What sorts of issues might this person be dealing with?; 3) What strategies could be used to help this person?; and 4) If there were lots of people like this, what could health services / community organisations do to improve their outcomes? During the workshops, community members will work together to discuss ideas for how to improve information and services for people with IBD.

Activities:

- Ideas generation workshops with health professionals, people with IBD and their carers will be held in February and March 2021.
- To maximise participation, the vignettes and the four questions will be provided to health professionals via email or Qualtrics.
- Thematic analysis of the workshop / email findings (April/May 2021) will provide the information for intervention co-design and testing in Ophelia phase 2.

Comments:

- Ethics application for Ophelia phase 2 will be informed by the workshop findings.
- Ophelia phase 2 is expected to start by June 2021.

3. Results to date

3.1 Demographics

The survey was undertaken online using Qualtrics and posted to potential participants. Recruitment took place in Victoria (CCA membership list and website, Monash Health Gastroenterology, Monash Children's Hospital) and New South Wales (Liverpool Hospital Gastroenterology). The online survey period was from 10 August to 31 October 2020. A total of 1,313 responses were collected online and a further 48 questionnaires were received by post. Following exclusion of incomplete questionnaires, 868 questionnaires for persons living with IBD and 85 for carers were included for analysis.

Among the respondents who were persons living with IBD, 63.5% were female and the mean age was 49.3 years (SD = 17.2) with 9.2% aged 15 – 25 years. Respondents were mainly Australian born (81.9%) and most of them spoke English at home (96.9%). The respondents were generally better educated, with close to half (45.8%) with a university education or above. A third (34.6%) were working full time and 24.0% were retired. About a quarter of the respondents resided in regional or remote areas (26.7%) and 13.6% of them lived alone. For IBD condition, 61.4% had Crohn's disease and 36.2% had ulcerative colitis, with 61.3% of the respondents diagnosed 10 or more years ago. Most of the respondents (62.9%) did not undergo any surgery and 5.5% had 5 or more surgeries. Over a quarter of the respondents (29.3%) were in remission, 10.6% were experiencing constantly active symptoms and 13.1% experiencing often active symptoms. Half of the respondents (50.3%) had their condition managed by private specialist, 21.9% were managed by public IBD specific outpatient clinic, and 55.2% felt that their IBD management was affected by the Covid-19 pandemic. Apart from IBD, 74.7% reported having other chronic health conditions with arthritis (32.9%) being the main condition. Over a quarter of the respondents (28.0%) reported anxiety and 15.6% of the respondents reported both anxiety and depression. See Table 1.

Table 1. Demographic data for persons with IBD (n = 868)

Characteristics	**n (%)**
Age	
Mean: Year (SD) Range: 15 – 89	49.3 (17.2)
15 – 25	80 (9.2)
26 – 40	220 (25.3)
41 – 55	216 (24.9)
56 – 70	248 (28.6)
71 or above	101 (11.6)
Sex	
Female	551 (63.5)
Male	316 (36.4)
Australian born	711 (81.9)
Spoke English at home	841 (96.9)
Aboriginal and Torres Strait Islander	6 (0.7)
Education	
Primary school	13 (1.5)
High school	208 (24.0)
Certificate/Diploma	246 (28.3)
University	251 (28.9)
Postgraduate	147 (16.9)
Residence	
Major city	625 (72.0)
Inner regional	176 (20.3)
Outer regional	48 (5.5)
Remote or very remote	8 (0.9)
Number of household members	
Mean (SD) Range: 1 – 9	2.7 (1.3)
Lived alone	118 (13.6)

Demographic data for persons with IBD (cont'd)

Characteristics	n (%)
Employment status	
Full time	300 (34.6)
Part time	184 (21.2)
Retired	208 (24.0)
Other	175 (20.1)
Confirmed diagnosis	
Crohn's disease	533 (61.4)
Ulcerative colitis	314 (36.2)
Number of years diagnosed with IBD	
Mean (SD) Range: 0 – 67	15.9 (12.7)
Less than 1 year	38 (4.4)
1 – 4 years	155 (17.9)
5 – 9 years	131 (15.1)
10 or more years	532 (61.3
Number of surgeries	
Mean (SD) Range: 0 – 32	1.0 (2.5)
No surgery	546 (62.9)
1 surgery	63 (7.3)
2 – 4 surgeries	102 (11.8)
5 or more surgeries	48 (5.5)
Manitoba Index	
Constantly active	92 (10.6)
Often active	114 (13.1)
Sometimes active	155 (17.9)
Occasionally active	129 (14.9)
Rarely active	138 (15.9)
I was well	254 (29.3)
IBD Management	
Public outpatient clinic	73 (8.4)
Public IBD specific outpatient clinic	190 (21.9)
Private specialist	437 (50.3)
General practitioner	96 (11.1)
Other	16 (1.8)
Perceived health status	
Very poor	22 (2.5)
Poor	74 (8.5)
Fair	227 (26.2)
Good	233 (26.8)
Very good	230 (26.5)
Excellent	82 (9.4)
IBD management affected by Covid-19	479 (55.2)

Demographic data for persons with IBD (cont'd)

Characteristics	n (%)
Long-standing illness	
None other than IBD	220 (25.3)
Arthritis	286 (32.9)
Back pain	179 (20.6)
Cancer	26 (3.0)
Diabetes	57 (6.6)
Heart problems	116 (13.4)
Kidney problems	27 (3.1)
Lung problems	96 (11.1)
Anxiety	243 (28.0)
Depression	179 (20.6)
Both anxiety and depression	135 (15.6)
Other	223 (25.7)
Have private health insurance	629 (72.5)
Have healthcare card	327 (37.7)

Carer respondents were predominately female (82.4%) with the mean age of 51.6 (SD = 11.5). Even though 20% of the respondents were born overseas, all of them spoke English at home. The carers were educated with almost a quarter of them (24.7%) with postgraduate qualifications. Most carers were working full time (41.2%) or part time (25.9%) and only 11.8% were retired. Over a quarter (27.1%) resided in regional or remote areas. The management of IBD for the person they care for was mainly handled by private specialist (40.0%) and public IBD specific outpatient clinic (34.1%). They considered the health of the person they care for as good to excellent (63.6%). Among the carers, 44.7% reported having chronic health conditions and 14.1% experienced anxiety, depression or other mental health issue. See Table 2.

Table 2. Demographic data for carers (n = 85)

Characteristics	n (%)
Age	
Mean (SD) Range: 26 – 91	51.6 (11.5)
25 – 55	56 (65.9)
56 – 91	28 (32.9)
Sex	
Female	70 (82.4)
Male	15 (17.6)
Australian born	68 (80.0)
Spoke English at home	85 (100.0)
Aboriginal and Torres Strait Islander	0 (0.0)
Education	
High school	9 (10.6)
Certificate/Diploma	26 (30.6)
University	27 (31.8)
Postgraduate	21 (24.7)

Demographic data for carers (cont'd)

Characteristics	**n (%)**
Residence	
Major city	59 (69.4)
Inner regional	16 (18.8)
Outer regional	6 (7.1)
Remote or very remote	1 (1.2)
Number of household members	
Mean (SD) Range: 2 - 6	3.5 (1.0)
Two members	17 (20.0)
Employment status	
Full time	35 (41.2)
Part time	22 (25.9)
Retired	10 (11.8)
Other	16 (18.7)
IBD management of the person cared for	
Public outpatient clinic	13 (15.3)
Public IBD specific outpatient clinic	29 (34.1)
Private specialist	34 (40.0)
General practitioner	4 (4.7)
Other	5 (5.9)
Perceived health status of the person cared for	
Very poor	4 (4.7)
Poor	10 (11.8)
Fair	17 (20.0)
Good	23 (27.1)
Very good	25 (29.4)
Excellent	6 (7.1)
IBD management affected by Covid-19	53 (62.4)
No long-standing illness	40 (47.1)
Presence of any long-standing illness^	38 (44.7)
Presence of mental health condition*	12 (14.1)
Presence of both anxiety and depression	1 (1.2)
Owned private health insurance	66 (77.6)
Owned healthcare card	19 (22.4)

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

*Includes anxiety, depression and bi-polar.

3.2 Health Literacy

For persons living with IBD, the highest mean score for the eHLQ and the first 5 scales of the HLQ with score range of 1 – 4 (strongly disagree to strongly agree) was for 'Feeling understood and supported by healthcare providers' (3.28, SD 0.53) and the lowest mean score was for 'Motivated to engage with digital services' (2.74, SD 0.52). For the last 4 scales, with score range of 1 – 5 (cannot do or always difficult to always easy), the highest mean score was for

‘Understanding health information well enough to know what to do’ (4.07, SD 0.54) and the lowest was for ‘Navigating the healthcare system’ (3.59, SD 0.69). See Table 3 for details.

For carers, the highest mean score for the eHLQ and the first 5 scales of the HLQ with score range of 1 – 4 (strongly disagree to strongly agree) was for ‘Actively managing my health’ (3.15, SD 0.46) and the lowest mean score was for ‘Social support for health’ (2.54, SD 0.63). For the last 4 scales with score range of 1 – 5 (cannot do or always difficult to always easy), the highest mean score was for ‘Understanding health information well enough to know what to do’ (4.02, SD 0.55) and the lowest was for ‘Navigating the healthcare system’ (3.25, SD 0.75). See Table 3.

Table 3. Health Literacy Scores for Persons with IBD (n = 868) and Carers (n = 85)

	Persons with IBD Mean (SD) [95%CI]	**Carers Mean (SD) [95%CI]**
eHLQ Scale	Score Range: 1 (lowest) – 4 (highest)	
5. Motivated to engage with digital services	2.74 (0.52) [2.70 - 2.77]	2.64 (0.53) [2.52 - 2.75]
HLQ Scale		
1. Feeling understood and supported by healthcare providers	3.28 (0.53) [3.24 - 3.31]	3.07 (0.58) [2.94 - 3.19]
2. Having sufficient information to manage my health	2.88 (0.55) [2.85 - 2.92]	2.66 (0.68) [2.52 - 2.81]
3. Actively managing my health	3.13 (0.46) [3.09 - 3.16]	3.15 (0.46) [3.05 - 3.25]
4. Social support for health	2.91 (0.59) [2.87 - 2.95]	2.54 (0.63) [2.40 - 2.68]
5. Appraisal of health information	2.91 (0.47) [2.88 - 2.95]	2.95 (0.43) [2.86 - 3.05]
	Score Range: 1 (lowest) – 5 (highest)	
6. Ability to actively engage with healthcare providers	3.76 (0.74) [3.71 - 3.81]	3.44 (0.88) [3.25 - 3.64]
7. Navigating the healthcare system	3.59 (0.69) [3.54 - 3.63]	3.25 (0.75) [3.08 - 3.41]
8. Ability to find good health information	3.77 (0.61) [3.73 - 3.81]	3.66 (0.57) [3.54 - 3.79]
9. Understanding health information well enough to know what to do	4.07 (0.54) [4.04 - 4.11]	4.02 (0.55) [3.90 - 4.13]

3.3 Cluster descriptions – persons with IBD

The cluster analysis for persons with IBD identified 13 clusters with different patterns of health literacy strengths and weaknesses (Table 4). Two clusters (Clusters A and B) have generally higher scores across all scales while the remaining 11 clusters (Clusters C to M) demonstrate various strengths and weaknesses in different health literacy domains.

Table 4. Health Literacy Scores of the 13 Clusters of Persons with IBD

Cluster	Number of people in clusters	% in clusters	eHLQ 5. Motivated to engage with digital services	1. Feeling understood and supported by health care providers	2. Having sufficient information to manage my health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with healthcare providers	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information well enough to know what to do
			Score range: 1 (lowest)–4 (highest)						Score range: 1 (lowest)–5 (highest)			
A	71	8.2%	3.20	3.89	3.72	3.57	3.71	3.50	4.79	4.53	4.60	4.74
B	114	13.2%	3.04	3.68	3.22	3.59	3.27	3.27	4.11	3.92	4.11	4.32
C	40	4.6%	2.95	3.36	3.13	3.13	2.73	3.15	4.41	4.27	4.49	4.72
D	68	7.9%	2.38	3.72	3.19	2.90	3.26	2.64	4.38	4.14	4.12	4.54
E	74	8.5%	2.98	3.59	2.83	2.96	3.20	3.08	4.00	3.62	3.77	4.00
F	37	4.3%	3.36	3.18	2.99	3.52	2.83	3.31	3.32	3.36	3.76	3.83
G	158	18.2%	2.67	3.09	2.87	2.86	2.91	2.82	3.82	3.70	3.86	4.03
H	86	9.9%	2.19	3.17	2.78	2.93	2.58	2.51	3.62	3.47	3.36	3.83
I	109	12.6%	2.82	3.06	2.47	3.17	2.70	2.75	3.16	3.00	3.26	3.58
J	46	5.3%	2.72	2.32	2.46	3.09	2.31	2.88	2.83	2.87	3.66	4.20
K	36	4.2%	2.12	2.80	2.13	2.91	2.16	2.57	2.95	2.67	2.99	3.53
L	18	2.1%	2.41	2.57	2.04	2.59	2.09	2.32	1.99	1.91	2.17	2.79
M	9	1.0%	1.20	2.08	1.47	2.96	1.51	2.20	2.33	2.20	2.38	3.76

Note: The scores are highlighted using the traffic light system of colour coding as recommended in the Ophelia process. Cells coloured in green represented higher scores, the range of yellow represents medium scores and red indicates lower scores.

Each cluster has its own pattern and it will be combined with the related demographics to form the basis of the vignettes. Full details of the health literacy scores and demographics are presented in Appendix 1. The characteristics of the 13 clusters are as follows:

- Cluster A – Highly confident in using health information and services with good support
- Cluster B – Generally comfortable with using health information and services
- Cluster C – Good healthcare support and information use but social support may not always be available
- Cluster D – Good access to health information but appraising information may be challenging and do not see digital resources as useful
- Cluster E – Good relationship with healthcare providers but navigating the healthcare system may sometimes be difficult
- Cluster F – Limited engagement with healthcare providers but willing to manage health
- Cluster G – Access to healthcare acceptable and understand health information well if provided but managing health is not a priority

- Cluster H – Finding the right healthcare can be challenging with inadequate social support and access to health information
- Cluster I – Inadequate information and services support but attempt to take control of own health
- Cluster J – Low healthcare, social and information support but understand information well
- Cluster K – Low healthcare, social and information support and do not use digital health services
- Cluster L – Unable to engage with healthcare services, lack social support and have limited understanding of health information
- Cluster M – Lack of healthcare, social and information support but attempt to manage health

3.4 Cluster descriptions – carers

For carers, the cluster analysis identified 12 clusters with varying health literacy patterns (Table 5). The results led to some small clusters and they were retained due to the uniqueness of their health literacy patterns. Similar to the results of the persons with IBD, two clusters (Cluster A and B) have higher scores across all scales while the other nine clusters (Cluster C to L) show different strengths and weaknesses.

Table 5. Health Literacy Scores of the 12 Clusters of Carers

Cluster	Number of persons in clusters	Number in clusters (%)	eHLQ 5. Motivated to engage with digital services	1. Feeling understood and supported by health care	2. Having sufficient information to manage my health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with healthcare providers	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information well enough to know what to do
			Score range: 1 (lowest)–4 (highest)						Score range: 1 (lowest)–5 (highest)			
A	2	2.4%	3.70	3.88	4.00	3.70	3.70	3.90	4.80	4.75	4.90	5.00
B	7	8.3%	2.97	3.86	3.36	3.31	3.23	3.31	4.34	3.98	3.97	4.17
C	8	9.5%	2.83	3.53	3.09	3.73	2.43	3.63	3.73	3.48	4.08	4.80
D	11	13.1%	2.76	3.14	3.02	3.05	3.07	2.65	3.91	3.79	3.87	3.96
E	6	7.1%	2.50	3.33	2.75	3.03	2.20	2.67	4.10	3.75	4.07	4.67
F	12	14.3%	2.65	3.15	2.71	2.70	2.72	3.15	3.80	3.60	3.87	4.00
G	6	7.1%	3.37	2.79	2.50	3.67	2.43	3.17	2.63	2.78	3.77	3.90
H	12	14.3%	2.25	3.08	2.79	3.00	2.58	2.68	3.55	3.11	3.20	3.77
I	7	8.3%	2.43	2.64	2.18	2.60	2.14	2.57	2.83	2.57	3.43	3.83
J	2	2.4%	1.60	2.63	1.38	3.80	1.20	3.20	2.40	2.67	3.50	4.20
K	10	11.9%	2.28	2.33	1.70	3.22	1.94	2.64	2.20	2.13	2.74	3.20
L	1	1.2%	3.20	1.00	1.25	3.60	1.20	2.80	1.20	1.33	4.20	3.80

Note: The scores are highlighted using the traffic light system of colour coding as recommended in the Ophelia process. Cells coloured in green represented higher scores, the range of yellow represents medium scores and red indicates lower scores.

The clusters are to be combined with the related demographics to generate vignettes. Please see Appendix 2 for full detail descriptions of each cluster. The characteristics of the 12 clusters are as follows:

- Cluster A – Confident in using health information and services and well-supported
- Cluster B – Comfortable in using health information and services with good support
- Cluster C – Good understanding of health information but may not always get the right kind of care and have inadequate social support
- Cluster D – Have intermittent healthcare support and appraising information can be challenging
- Cluster E – Limited social support and may not always have access to good information
- Cluster F – Some support to health information and services, and generally rely on healthcare providers for health
- Cluster G – Inadequate healthcare and social support and likely to be managing health independently
- Cluster H – Inadequate healthcare and social support but attempt to take control of the health of the person they care for
- Cluster I – Limited relationships with healthcare providers and limited access and understanding of health information, with low social support
- Cluster J – Lack of access to health information and very low healthcare and social support but actively managing the health of the person they care for
- Cluster K – Limited access to and understanding of health information and limited support but are thinking about health
- Cluster L – low healthcare and social support but good access and understanding of health information while also actively managing health

3.5 Example vignette – Cluster I: Persons with IBD

Nick is 23 and finished university last year. He is still living with his parents in Ballarat. He was diagnosed with Crohn's disease three years ago and the condition really disrupted his studies. His symptoms are often active, and Nick is not sure he can handle a full-time job. Also, the pain and bleeding prevent him from going out with his friends as much as he wants. Sometimes, he feels that his friends think he is weird.

He has been able to see the same private specialist since his diagnosis. The medications sometimes work, sometimes don't, and he finds it difficult to describe his conditions to the specialist. He experiences mood swings occasionally and has no idea that this is one of the side effects of some of his medications. He tries to look up information on the internet, but the amount of information is overwhelming and confusing. He is feeling very depressed about this future.

4. Timeline

Deliverables/ Milestones	Key Dates	Status / planned
Fortnightly meetings	March	Ongoing
Participant engagement planning meeting	27 April 2020	Complete
Ethics approval for Ophelia phase 1	27 July 2020	Complete
Questionnaire administration	10 August 2020	16 Oct 2020
Data analysis	November	December
Vignette development	December 2020	Feb 2021
Ideas generation workshops	Feb 2021	March 2021
Phase 1 progress report	April 2021	
Ethics Ophelia phase 2 – co-design and testing	March 2021	April 2021
Co-design workshops	May 2021	June 2021
Development and testing of interventions	From June 2021	
Phase 2 progress report	Dec 2021	
Ophelia phase 3 – implementation and evaluation	2022	Sept 2023

Appendix 1 – Clusters for persons with IBD

Cluster	Number in clusters	% in clusters	eHLQ 5. Motivated to engage with digital services	1. Feeling understood and supported by health care providers	2. Having sufficient information to manage my health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with healthcare providers	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information well enough to know what to do
			Score range: 1 (lowest)–4 (highest)						Score range: 1 (lowest)–5 (highest)			
A	71	8.2%	3.20	3.89	3.72	3.57	3.71	3.50	4.79	4.53	4.60	4.74
B	114	13.2%	3.04	3.68	3.22	3.59	3.27	3.27	4.11	3.92	4.11	4.32
C	40	4.6%	2.95	3.36	3.13	3.13	2.73	3.15	4.41	4.27	4.49	4.72
D	68	7.9%	2.38	3.72	3.19	2.90	3.26	2.64	4.38	4.14	4.12	4.54
E	74	8.5%	2.98	3.59	2.83	2.96	3.20	3.08	4.00	3.62	3.77	4.00
F	37	4.3%	3.36	3.18	2.99	3.52	2.83	3.31	3.32	3.36	3.76	3.83
G	158	18.2%	2.67	3.09	2.87	2.86	2.91	2.82	3.82	3.70	3.86	4.03
H	86	9.9%	2.19	3.17	2.78	2.93	2.58	2.51	3.62	3.47	3.36	3.83
I	109	12.6%	2.82	3.06	2.47	3.17	2.70	2.75	3.16	3.00	3.26	3.58
J	46	5.3%	2.72	2.32	2.46	3.09	2.31	2.88	2.83	2.87	3.66	4.20
K	36	4.2%	2.12	2.80	2.13	2.91	2.16	2.57	2.95	2.67	2.99	3.53
L	18	2.1%	2.41	2.57	2.04	2.59	2.09	2.32	1.99	1.91	2.17	2.79
M	9	1.0%	1.20	2.08	1.47	2.96	1.51	2.20	2.33	2.20	2.38	3.76

Note: The scores are highlighted using the traffic light system of colour coding as recommended in the Ophelia process. Cells coloured in green represented higher scores, the range of yellow represents medium scores and red indicates lower scores.

Cluster	% in clusters	Overall average	Female (%)	Mean age	Aged 15 -25 (%)	Aged 26 - 40 (%)	Aged 41 - 55 (%)	Aged 46 - 70 (%)	Aged 71 or above (%)	Diagnosed Crohn’ s disease (%)	Diagnosed Ulcerative colitis (%)
A	8.2%	4.04	52.1%	52.2	11.3%	19.7%	18.3%	31.0%	19.7%	66.2%	31.0%
B	13.2%	3.67	61.4%	49.4	11.4%	20.2%	31.6%	24.6%	12.3%	60.5%	37.7%
C	4.6%	3.66	67.5%	49.5	5.0%	27.5%	30.0%	25.0%	10.0%	65.0%	35.0%
D	7.9%	3.54	66.2%	50.1	4.4%	23.5%	29.4%	36.8%	5.9%	66.2%	33.8%
E	8.5%	3.42	56.8%	49.1	9.5%	29.7%	17.6%	28.4%	14.9%	63.5%	33.8%
F	4.3%	3.36	59.5%	48.8	18.9%	13.5%	24.3%	35.1%	8.1%	59.5%	37.8%
G	18.2%	3.28	57.0%	49.7	7.0%	24.7%	28.5%	31.0%	8.9%	65.8%	32.9%
H	9.9%	3.06	69.8%	52.1	7.0%	18.6%	24.4%	32.6%	16.3%	51.2%	44.2%
I	12.6%	3.01	68.8%	44.4	14.7%	38.5%	17.4%	16.5%	12.8%	63.3%	35.8%
J	5.3%	2.95	73.9%	45.2	6.5%	39.1%	23.9%	28.3%	2.2%	43.5%	47.8%
K	4.2%	2.69	75.0%	50.9	11.1%	13.9%	30.6%	33.3%	8.3%	58.3%	36.1%
L	2.1%	2.28	72.2%	48.2	0.0%	44.4%	27.8%	16.7%	11.1%	66.7%	33.3%
M	1.0%	2.23	77.8%	56.7	0.0%	11.1%	11.1%	66.7%	11.1%	55.6%	33.3%

Cluster	% in clusters	Lived alone (%)	Australian born (%)	Spoke English at home (%)	Lived in major cities (%)	Lived in inner regional area (%)	Lived in outer regional or remote area (%)	High school or below (%)	Trade/Certificate/Diploma (%)	University undergraduate (%)	University postgraduate (%)
A	8.2%	11.3%	78.9%	95.8%	78.9%	16.9%	4.2%	26.8%	25.4%	25.4%	22.5%
B	13.2%	16.7%	79.8%	99.1%	74.6%	21.9%	3.5%	18.4%	19.3%	38.6%	23.7%
C	4.6%	17.5%	82.5%	92.5%	70.0%	17.5%	7.5%	27.5%	27.5%	27.5%	17.5%
D	7.9%	8.8%	85.3%	100.0%	82.4%	13.2%	4.4%	22.1%	20.6%	35.3%	22.1%
E	8.5%	9.5%	86.5%	100.0%	77.0%	14.9%	6.8%	29.7%	36.5%	25.7%	8.1%
F	4.3%	13.5%	75.7%	94.6%	89.2%	10.8%	0.0%	29.7%	29.7%	24.3%	16.2%
G	18.2%	13.9%	84.8%	94.3%	70.3%	21.5%	7.0%	22.2%	36.1%	25.3%	15.8%
H	9.9%	23.3%	77.9%	96.5%	65.1%	24.4%	5.8%	31.4%	38.4%	17.4%	11.6%
I	12.6%	9.2%	81.7%	95.4%	67.0%	26.6%	5.5%	22.0%	28.4%	35.8%	12.8%
J	5.3%	15.2%	89.1%	97.8%	65.2%	19.6%	15.2%	30.4%	10.9%	32.6%	26.1%
K	4.2%	13.9%	72.2%	100.0%	63.9%	22.2%	11.1%	38.9%	25.0%	19.4%	16.7%
L	2.1%	5.6%	83.3%	100.0%	66.7%	27.8%	5.6%	27.8%	27.8%	38.9%	5.6%
M	1.0%	11.1%	88.9%	100.0%	44.4%	11.1%	44.4%	22.2%	33.3%	33.3%	11.1%

Cluster	% in clusters	Working full time (%)	Working part time (%)	Retired (%)	Owned private insurance (%)	Owned healthcare card (%)	Perceived health poor to very poor (%)	Perceived health fair (%)	Covid-19 changed way of management (%)
A	8.2%	33.8%	5.6%	36.6%	77.5%	45.1%	7.0%	8.5%	57.7%
B	13.2%	28.1%	28.1%	22.8%	80.7%	32.5%	4.4%	22.8%	57.0%
C	4.6%	30.0%	27.5%	25.0%	75.0%	37.5%	10.0%	15.0%	50.0%
D	7.9%	41.2%	22.1%	22.1%	83.8%	29.4%	2.9%	16.2%	48.5%
E	8.5%	27.0%	25.7%	25.7%	71.6%	39.2%	6.8%	24.3%	63.5%
F	4.3%	21.6%	21.6%	32.4%	73.0%	54.1%	16.2%	24.3%	62.2%
G	18.2%	42.4%	19.0%	24.7%	69.6%	33.5%	5.7%	26.6%	49.4%
H	9.9%	33.7%	17.4%	24.4%	70.9%	44.2%	8.1%	29.1%	47.7%
I	12.6%	32.1%	26.6%	19.3%	60.6%	41.3%	19.3%	33.0%	67.0%
J	5.3%	52.2%	23.9%	8.7%	73.9%	28.3%	28.3%	37.0%	56.5%
K	4.2%	33.3%	16.7%	25.0%	69.4%	38.9%	25.0%	55.6%	50.0%
L	2.1%	38.9%	16.7%	16.7%	72.2%	22.2%	38.9%	33.3%	55.6%
M	1.0%	22.2%	11.1%	11.1%	55.6%	55.6%	22.2%	44.4%	33.3%

Cluster	Diagnosed less than 1 year (%)	Diagnosed 1 - 4 years (%)	Diagnosed 5 - 9 years (%)	Diagnosed 10 or more years (%)	Undergone IBD surgery (%)	Had 1 surgery (%)	Had 2 - 4 surgeries (%)	Had 5 or more surgeries (%)	Managed by public outpatient clinic (%)	Managed by public IBD specific outpatient clinic (%)	Managed by private specialist (%)	Managed by GP (%)
A	2.8%	7.0%	15.5%	74.6%	45.1%	5.6%	16.9%	2.8%	7.0%	25.4%	49.3%	9.9%
B	3.5%	13.2%	15.8%	66.7%	34.2%	7.9%	5.3%	8.8%	3.5%	14.0%	64.9%	9.6%
C	5.0%	10.0%	25.0%	55.0%	42.5%	7.5%	15.0%	2.5%	15.0%	25.0%	45.0%	7.5%
D	0.0%	7.4%	16.2%	75.0%	45.6%	7.4%	16.2%	10.3%	7.4%	11.8%	64.7%	14.7%
E	4.1%	29.7%	13.5%	52.7%	32.4%	5.4%	8.1%	8.1%	8.1%	31.1%	52.7%	4.1%
F	5.4%	24.3%	16.2%	54.1%	35.1%	2.7%	13.5%	8.1%	13.5%	18.9%	40.5%	8.1%
G	3.2%	21.5%	17.1%	57.0%	38.0%	8.2%	14.6%	2.5%	10.1%	27.2%	46.8%	9.5%
H	1.2%	11.6%	9.3%	76.7%	34.9%	7.0%	10.5%	7.0%	7.0%	23.3%	46.5%	14.0%
I	8.3%	26.6%	11.0%	52.3%	34.9%	7.3%	11.0%	1.8%	11.0%	21.1%	46.8%	12.8%
J	13.0%	19.6%	15.2%	52.2%	19.6%	4.3%	8.7%	0.0%	6.5%	23.9%	37.0%	13.0%
K	5.6%	19.4%	22.2%	50.0%	50.0%	13.9%	13.9%	11.1%	8.3%	19.4%	50.0%	11.1%
L	11.1%	27.8%	11.1%	44.4%	16.7%	11.1%	5.6%	0.0%	5.6%	11.1%	61.1%	22.2%
M	0.0%	11.1%	11.1%	66.7%	66.7%	11.1%	22.2%	22.2%	11.1%	22.2%	0.0%	44.4%

Cluster	IBD constantly active (%)	IBD often active (%)	IBD sometimes active (%)	IBD occasionally active (%)	IBD rarely active (%)	IBD remission (%)	No or little confident about daily treatment (%)	No or little confident about plan of action (%)	No or little confident about how diet affects (%)	No or little confident about other health problems (%)	No or little confident about how feeling can affect (%)
A	5.6%	8.5%	14.1%	8.5%	16.9%	47.9%	2.8%	5.6%	12.7%	5.6%	8.5%
B	9.6%	14.0%	14.0%	14.0%	17.5%	33.3%	7.9%	13.2%	15.8%	28.1%	13.2%
C	15.0%	10.0%	20.0%	12.5%	15.0%	30.0%	7.5%	12.5%	10.0%	12.5%	0.0%
D	5.9%	5.9%	16.2%	17.6%	16.2%	42.6%	0.0%	1.5%	22.1%	25.0%	19.1%
E	5.4%	14.9%	16.2%	17.6%	14.9%	33.8%	13.5%	24.3%	35.1%	39.2%	20.3%
F	8.1%	16.2%	21.6%	24.3%	10.8%	24.3%	13.5%	32.4%	24.3%	40.5%	16.2%
G	8.9%	12.7%	15.2%	14.6%	17.1%	31.0%	12.0%	20.3%	26.6%	36.7%	20.3%
H	11.6%	15.1%	15.1%	15.1%	16.3%	26.7%	16.3%	31.4%	25.6%	46.5%	23.3%
I	17.4%	13.8%	22.0%	14.7%	17.4%	16.5%	45.0%	55.0%	37.6%	69.7%	38.5%
J	19.6%	17.4%	23.9%	13.0%	15.2%	13.0%	37.0%	45.7%	47.8%	45.7%	28.3%
K	11.1%	19.4%	36.1%	16.7%	11.1%	5.6%	52.8%	61.1%	50.0%	55.6%	38.9%
L	16.7%	0.0%	22.2%	22.2%	11.1%	27.8%	66.7%	83.3%	55.6%	72.2%	27.8%
M	11.1%	44.4%	0.0%	0.0%	11.1%	33.3%	33.3%	66.7%	44.4%	66.7%	22.2%

Cluster	No long-standing illness other than IBD (%)	Arthritis (%)	Backpain (%)	Cancer (%)	Diabetes (%)	Heart problem (%)	Kidney problem (%)	Lung problem (%)	Anxiety (%)	Depression (%)	Both anxiety and depression (%)	Other long-standing illness (%)
A	32.4%	32.4%	12.7%	2.8%	12.7%	14.1%	4.2%	12.7%	18.3%	8.5%	5.6%	18.3%
B	26.3%	34.2%	18.4%	4.4%	3.5%	13.2%	3.5%	13.2%	25.4%	18.4%	14.9%	27.2%
C	22.5%	30.0%	20.0%	0.0%	0.0%	10.0%	0.0%	17.5%	35.0%	22.5%	17.5%	15.0%
D	30.9%	22.1%	8.8%	1.5%	4.4%	10.3%	1.5%	7.4%	26.5%	16.2%	11.8%	29.4%
E	23.0%	33.8%	16.2%	0.0%	8.1%	13.5%	4.1%	9.5%	25.7%	21.6%	16.2%	25.7%
F	18.9%	35.1%	21.6%	8.1%	10.8%	10.8%	2.7%	13.5%	24.3%	27.0%	13.5%	32.4%
G	29.7%	33.5%	18.4%	3.2%	6.3%	14.6%	3.2%	10.1%	18.4%	13.3%	8.9%	19.0%
H	22.1%	32.6%	27.9%	3.5%	8.1%	14.0%	3.5%	8.1%	26.7%	23.3%	18.6%	22.1%
I	22.0%	33.0%	24.8%	1.8%	6.4%	16.5%	2.8%	11.9%	39.4%	25.7%	22.0%	29.4%
J	21.7%	28.3%	28.3%	2.2%	6.5%	8.7%	0.0%	6.5%	43.5%	39.1%	30.4%	39.1%
K	27.8%	44.4%	33.3%	5.6%	5.6%	13.9%	2.8%	8.3%	38.9%	25.0%	16.7%	33.3%
L	16.7%	38.9%	33.3%	5.6%	5.6%	5.6%	0.0%	11.1%	44.4%	44.4%	33.3%	33.3%
M	0.0%	44.4%	33.3%	11.1%	0.0%	33.3%	22.2%	22.2%	44.4%	22.2%	22.2%	44.4%

Cluster	Taking 1 Aminosalicylates (%)	Taking 1 Corticosteroids (%)	Taking 1 Immunomodulators (%)	Taking 1 Biological agents (%)	Taking 1 Antibiotics (%)	Taking 1 Opioids/analgesics (%)	Taking 1 Psychotropics (%)	Other medication (%)	Average number of medication types
A	40.8%	12.7%	38.0%	50.7%	0.0%	0.0%	7.0%	39.4%	3.3
B	38.6%	10.5%	35.1%	47.4%	4.4%	5.3%	9.6%	44.7%	3.1
C	35.0%	12.5%	20.0%	42.5%	0.0%	7.5%	15.0%	50.0%	2.5
D	41.2%	7.4%	39.7%	48.5%	1.5%	1.5%	8.8%	41.2%	2.6
E	28.4%	12.2%	47.3%	55.4%	4.1%	2.7%	8.1%	35.1%	2.8
F	43.2%	16.2%	29.7%	35.1%	5.4%	2.7%	2.7%	48.6%	3.1
G	35.4%	8.2%	39.9%	46.8%	0.6%	3.2%	3.8%	38.0%	2.8
H	47.7%	16.3%	30.2%	38.4%	2.3%	3.5%	5.8%	34.9%	3.0
I	35.8%	11.0%	37.6%	37.6%	0.9%	4.6%	11.0%	42.2%	2.7
J	43.5%	17.4%	39.1%	39.1%	0.0%	4.3%	13.0%	32.6%	2.6
K	36.1%	8.3%	36.1%	44.4%	2.8%	5.6%	8.3%	47.2%	3.0
L	33.3%	5.6%	38.9%	44.4%	0.0%	16.7%	5.6%	16.7%	1.7
M	22.2%	0.0%	33.3%	22.2%	0.0%	33.3%	11.1%	55.6%	3.3

Cluster A – Highly confident in using health information and services with good support

This cluster accounts for 8.2% of the sample. It has the highest scores among the 13 clusters across all scales except for the eHLQ scale Motivated to engage with digital services and Scale 3 Actively managing my health, although these are still the second highest scores for these scales. This cluster has the highest proportion of people aged 71 or above (19.7%) comparing to the other clusters. Almost half have university or above education while a third of them are retired, which is the highest proportion among all 13 clusters. Over 70% of the people in this cluster have a long history of IBD (diagnosed 10 or more years ago) and almost half are in remission, the highest among all clusters. Almost half have their conditions managed by private specialists. Most people indicated that they have good knowledge of IBD conditions. About a third did not have other chronic health conditions apart from IBD (32.4%), the highest among all other clusters. Arthritis was the main other health concern, but most perceived their health as good to excellent.

Cluster A Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
3.20	3.89	3.72	3.57	3.71	3.50	4.79	4.53	4.60	4.74

Cluster A Demographics (n = 71)

Characteristics	%*	Characteristics	%*
% of sample	8.2	Medication:	
Mean age: Year (SD)	52.2 (19.7)	Taking 1 Aminosalicylates	40.8
Female	52.1	Taking 1 Corticosteroids	12.7
Lived alone	11.3	Taking 1 Immunomodulators	38.0
Lived in inner regional area	16.9	Taking 1 Biological agents	50.7
Lived in outer regional/remote area	4.2	Taking 1 Antibiotics	0.0
University or above	25.4	Taking 1 Opioids/analgesics	0.0
University postgraduate	22.5	Taking 1 Psychotropics	7.0
Working full time	33.8	Taking other medication	39.4
Retired	36.6	Average number of medication types (SD)	3.3 (3.2)
Owned private insurance	77.5	No or little confident about:	
Owned healthcare card	45.1	Daily treatment	2.8
Diagnosed Crohn's disease	66.2	Plan of action	5.6
Diagnosed Ulcerative colitis	31.0	How diet affects	12.7
Diagnosed 10 or more years	74.6	Other health problems	5.6
Undergone IBD surgery	45.1	How feeling can affect	8.5
IBD constantly active	5.6	Perceived health poor to very poor	7.0
IBD often active	8.5	Perceived health fair	8.5
IBD sometimes active	14.1	No long-standing illness other than IBD	32.4
IBD occasionally active	8.5	Arthritis	32.4
IBD rarely active	16.9	Backpain	12.7
IBD remission	47.9	Diabetes	12.7

Cluster A Demographics (cont'd)

Characteristics	%*	Characteristics	%*
IBD Managed by:		Heart problem	14.1
Public outpatient clinic	7.0	Lung problem	12.7
Public IBD specific outpatient clinic	25.4	Anxiety	18.3
Private specialist	49.3	Depression	8.5
GP	9.9	Both anxiety and depression	5.6
Covid-19 changed management	57.7	Other long-standing illness	18.3

*% unless otherwise stated

Cluster B – Generally comfortable with using health information and services

Making up 13.2% of the sample (the second largest cluster), cluster B has the highest score in Scale 3 Actively managing my health, with all the other scales scores in the higher end of the score ranges even though they are lower than those of Cluster A. The average mean age of this cluster is lower than cluster A with over half of the participants aged 41 – 70. This is a cluster with the highest proportion of people with university or above education. Over 65% were diagnosed 10 or more years ago and about a third are in remission. Almost two-thirds have their condition managed by private specialists, the highest among all clusters. While most people indicated good knowledge of IBD, over a quarter were not confident about understanding other health problems that they could get because of IBD. Almost a quarter (22.8%) considered their health as just fair.

Cluster B Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
3.04	3.68	3.22	3.59	3.27	3.27	4.11	3.92	4.11	4.32

Cluster B Demographics (n = 114)

Characteristics	%*	Characteristics	%*
% of sample	13.2	Medication:	
Mean age: Year (SD)	49.4 (16.6)	Taking 1 Aminosalicylates	38.6
Female	61.4	Taking 1 Corticosteroids	10.5
Lived alone	16.7	Taking 1 Immunomodulators	35.1
Lived in inner regional area	21.9	Taking 1 Biological agents	47.4
Lived in outer regional/remote area	3.5	Taking 1 Antibiotics	4.4
University undergraduate	38.6	Taking 1 Opioids/analgesics	5.3
University postgraduate	23.7	Taking 1 Psychotropics	9.6
Working full time	28.1	Taking other medication	44.7
Retired	22.8	Average number of medication types (SD)	3.1 (2.9)
Owned private insurance	80.7	No or little confident about:	
Owned healthcare card	32.5	Daily treatment	7.9
Diagnosed Crohn's disease	60.5	Plan of action	13.2
Diagnosed Ulcerative colitis	37.7	How diet affects	15.8
Diagnosed 10 or more years	66.7	Other health problems	28.1
Undergone IBD surgery	34.2	How feeling can affect	13.2
IBD constantly active	9.6	Perceived health poor to very poor	4.4
IBD often active	14.0	Perceived health fair	22.8
IBD sometimes active	14.0	No long-standing illness other than IBD	26.3
IBD occasionally active	14.0	Arthritis	34.2
IBD rarely active	17.5	Backpain	18.4
IBD remission	33.3	Diabetes	3.5

Cluster B Demographics (cont'd)

Characteristics	%*	Characteristics	%*
Managed by:		Heart problem	13.2
Public outpatient clinic	3.5	Lung problem	13.2
Public IBD specific outpatient clinic	14.0	Anxiety	25.4
Private specialist	64.9	Depression	18.4
GP	9.6	Both anxiety and depression	14.9
Covid-19 changed management	57.0	Other long-standing illness	27.2

*% unless otherwise stated

Cluster C – Good healthcare support and information use but social support may not always be available

Cluster C is a small cluster with scores mostly in the higher end of the score ranges except for Scale 4 Social support for health, which indicates a potential weakness in social support. The age of this cluster mostly spread across 26 to 70 with only 5.0% are 15 – 25. More than half work full time or part time and 45% have a university education or above. Over half of the people were diagnosed with IBD 10 or more years ago and 30% were in remission. IBD care management was split between private specialists (45.0%) and public health services (40.0%), which is the highest proportion of people using public healthcare among all clusters. People in cluster C generally have good IBD knowledge. The other main chronic health issues they have are arthritis (30.0%) and anxiety (35.0%), with 15% of them taking psychotropic medications as well as IBD medications (the highest among all clusters).

Cluster C Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.95	3.36	3.13	3.13	2.73	3.15	4.41	4.27	4.49	4.72

Cluster C Demographics (n = 40)

Characteristics	%*	Characteristics	%*
% of sample	4.6	Medication:	
Mean age: Year (SD)	49.5 (16.3)	Taking 1 Aminosalicylates	35.0
Female	67.5	Taking 1 Corticosteroids	12.5
Lived alone	17.5	Taking 1 Immunomodulators	20.0
Lived in inner regional area	17.5	Taking 1 Biological agents	42.5
Lived in outer regional/remote area	7.5	Taking 1 Antibiotics	0.0
University undergraduate	27.5	Taking 1 Opioids/analgesics	7.5
University postgraduate	17.5	Taking 1 Psychotropics	15.0
Working full time	30.0	Taking other medication	50.0
Retired	25.0	Average number of medication types (SD)	2.5 (1.8)
Owned private insurance	75.0	No or little confident about:	
Owned healthcare card	37.5	Daily treatment	7.5
Diagnosed Crohn's disease	65.0	Plan of action	12.5
Diagnosed Ulcerative colitis	35.0	How diet affects	10.0
Diagnosed 10 or more years	55.0	Other health problems	12.5
Undergone IBD surgery	42.5	How feeling can affect	0.0
IBD constantly active	15.0	Perceived health poor to very poor	10.0
IBD often active	10.0	Perceived health fair	15.0
IBD sometimes active	20.0	No long-standing illness other than IBD	22.5
IBD occasionally active	12.5	Arthritis	30.0
IBD rarely active	15.0	Backpain	20.0
IBD remission	30.0	Diabetes	0.0

Cluster C Demographics (cont'd)

Characteristics	%*	Characteristics	%*
Managed by:		Heart problem	10.0
Public outpatient clinic	15.0	Lung problem	17.5
Public IBD specific outpatient clinic	25.0	Anxiety	35.0
Private specialist	45.0	Depression	22.5
GP	7.5	Both anxiety and depression	17.5
Covid-19 changed management	50.0	Other long-standing illness	15.0

*% unless otherwise stated

Cluster D – Good access to health information but appraising information may be challenging and do not see digital resources useful

Cluster D represents 7.9% of the study sample. People in this cluster have good healthcare and social support, but they may not be interested in using digital resources and may not be able to appraise health information very well. People in this cluster may not think about (or need to think about) managing their health, perhaps because this is the second largest cluster to have no chronic health conditions aside from IBD (30.9%) and 42.6% were in remission. This is another cluster where private specialists managed people's IBD and more than 80% of people have private health insurance, the highest among all clusters. The average age is similar to cluster C. Most people are well-educated, with 57.4% having university education or above. Most people indicate they have a good understanding of their daily treatment and a plan of action for when their IBD gets bad. However, about 20% do not have a good understanding how diet or their feelings affect their IBD, and how IBD might affect other health problems. Most people in this cluster consider their health to be good to excellent.

Cluster D Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.38	3.72	3.19	2.90	3.26	2.64	4.38	4.14	4.12	4.54

Cluster D Demographics (n = 68)

Characteristics	%*	Characteristics	%*
% of sample	7.9	Medication:	
Mean age: Year (SD)	50.1 (14.8)	Taking 1 Aminosalicylates	41.2
Female	66.2	Taking 1 Corticosteroids	7.4
Lived alone	8.8	Taking 1 Immunomodulators	39.7
Lived in inner regional area	13.2	Taking 1 Biological agents	48.5
Lived in outer regional/remote area	4.4	Taking 1 Antibiotics	1.5
University undergraduate	35.3	Taking 1 Opioids/analgesics	1.5
University postgraduate	22.1	Taking 1 Psychotropics	8.8
Working full time	41.2	Taking other medication	41.2
Retired	22.1	Average number of medication types (SD)	2.6 (1.9)
Owned private insurance	83.8	No or little confident about:	
Owned healthcare card	29.4	Daily treatment	0.0
Diagnosed Crohn's disease	66.2	Plan of action	1.5
Diagnosed Ulcerative colitis	33.8	How diet affects	22.1
Diagnosed 10 or more years	75.0	Other health problems	25.0
Undergone IBD surgery	45.6	How feeling can affect	19.1
IBD constantly active	5.9	Perceived health poor to very poor	2.9
IBD often active	5.9	Perceived health fair	16.2
IBD sometimes active	16.2	No long-standing illness other than IBD	30.9
IBD occasionally active	17.6	Arthritis	22.1

Cluster D Demographics (cont'd)

Characteristics	n (%)	Characteristics	n (%)
IBD rarely active	16.2	Backpain	8.8
IBD remission	42.6	Diabetes	4.4
Managed by:		Heart problem	10.3
Public outpatient clinic	7.4	Lung problem	7.4
Public IBD specific outpatient clinic	11.8	Anxiety	26.5
Private specialist	64.7	Depression	16.2
GP	14.7	Both anxiety and depression	11.8
Covid-19 changed management	48.5	Other long-standing illness	29.4

*% unless otherwise stated

Cluster E – Good relationship with healthcare providers but navigating the healthcare system may sometimes be difficult

People in cluster E make up 8.5% of the study sample and generally have a good relationship with their healthcare providers but may find navigating the health system challenging sometimes. They may not always have good access to health information but can usually understand information well. The average age is similar to Clusters B and C, and this is the cluster with the second lowest proportion of people with university education (33.8%). Cluster E has the largest proportion of people diagnosed with IBD 1 – 4 years (29.7%) ago, and a third of them are in remission (33.8%). While over half of the people have private specialists managing their condition, 31.1% rely on IBD specialist outpatient clinics, the highest proportion among all clusters. Over a third have little or no confidence in understanding how diet might affect their symptoms, and how IBD could lead to other health problems.

Cluster E Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.98	3.59	2.83	2.96	3.20	3.08	4.00	3.62	3.77	4.00

Cluster E Demographics (n = 74)

Characteristics	%*	Characteristics	%*
% of sample	8.5	Medication:	
Mean age: Year (SD)	49.1 (18.5)	Taking 1 Aminosalicylates	28.4
Female	56.8	Taking 1 Corticosteroids	12.2
Lived alone	9.5	Taking 1 Immunomodulators	47.3
Lived in inner regional area	14.9	Taking 1 Biological agents	55.4
Lived in outer regional/remote area	6.8	Taking 1 Antibiotics	4.1
University undergraduate	25.7	Taking 1 Opioids/analgesics	2.7
University postgraduate	8.1	Taking 1 Psychotropics	8.1
Working full time	27.0	Taking other medication	35.1
Retired	25.7	Average number of medication types (SD)	2.8 (2.4)
Owned private insurance	71.6	No or little confident about:	
Owned healthcare card	39.2	Daily treatment	13.5
Diagnosed Crohn's disease	63.5	Plan of action	24.3
Diagnosed Ulcerative colitis	33.8	How diet affects	35.1
Diagnosed 10 or more years	52.7	Other health problems	39.2
Undergone IBD surgery	32.4	How feeling can affect	20.3
IBD constantly active	5.4	Perceived health poor to very poor	6.8
IBD often active	14.9	Perceived health fair	24.3
IBD sometimes active	16.2	No long-standing illness other than IBD	23.0
IBD occasionally active	17.6	Arthritis	33.8
IBD rarely active	14.9	Backpain	16.2
IBD remission	33.8	Diabetes	8.1

Cluster E Demographics (cont'd)

Characteristics	%*	Characteristics	%*
Managed by:		Heart problem	13.5
Public outpatient clinic	8.1	Lung problem	9.5
Public IBD specific outpatient clinic	31.1	Anxiety	25.7
Private specialist	52.7	Depression	21.6
GP	4.1	Both anxiety and depression	16.2
Covid-19 changed management	63.5	Other long-standing illness	25.7

*% unless otherwise stated

Cluster F – Limited engagement with healthcare providers but willing to manage health

Cluster F is another small cluster in which people generally have an established relationship with a healthcare provider, but communication may have broken down and getting the care they need can be challenging. They may not always have good access to information but can usually understand information well when it is provided. They are taking responsibility for their own health and are also comfortable using digital resources for health. This is a cluster with the largest proportion of younger people (aged 15 – 25, 18.9%) comparing to the other clusters, but people aged 46 – 70 is the largest age group (35.1%) within Cluster F. None of the people in this cluster live in remote areas and only 10.8% of them live in regional areas. Most people were diagnosed 10 or more years ago, but about a quarter were diagnosed between 1 and 4 years ago (24.3%). About one in five sometimes experience active symptoms (21.6%) while a quarter of them (24.3%) are in remission. Most understand their daily treatment but many (40.5%) do not know about the other health problems they could get because of IBD.

Cluster F Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
3.36	3.18	2.99	3.52	2.83	3.31	3.32	3.36	3.76	3.83

Cluster F Demographics (n = 37)

Characteristics	%*	Characteristics	%*
% of sample	4.3	Medication:	
Mean age: Year (SD)	48.8 (18.9)	Taking 1 Aminosalicylates	43.2
Female	59.5	Taking 1 Corticosteroids	16.2
Lived alone	13.5	Taking 1 Immunomodulators	29.7
Lived in inner regional area	10.8	Taking 1 Biological agents	35.1
Lived in outer regional/remote area	0.0	Taking 1 Antibiotics	5.4
University undergraduate	24.3	Taking 1 Opioids/analgesics	2.7
University postgraduate	16.2	Taking 1 Psychotropics	2.7
Working full time	21.6	Taking other medication	48.6
Retired	32.4	Average number of medication types (SD)	3.1 (3.2)
Owned private insurance	73.0	No or little confident about:	
Owned healthcare card	54.1	Daily treatment	13.5
Diagnosed Crohn's disease	59.5	Plan of action	32.4
Diagnosed Ulcerative colitis	37.8	How diet affects	24.3
Diagnosed 10 or more years	54.1	Other health problems	40.5
Undergone IBD surgery	35.1	How feeling can affect	16.2
IBD constantly active	8.1	Perceived health poor to very poor	16.2
IBD often active	16.2	Perceived health fair	24.3
IBD sometimes active	21.6	No long-standing illness other than IBD	18.9
IBD occasionally active	24.3	Arthritis	35.1
IBD rarely active	10.8	Backpain	21.6

Cluster F Demographics (cont'd)

Characteristics	%*	Characteristics	%*
IBD remission	24.3	Diabetes	10.8
Managed by:		Heart problem	10.8
Public outpatient clinic	13.5	Lung problem	13.5
Public IBD specific outpatient clinic	18.9	Anxiety	24.3
Private specialist	40.5	Depression	27.0
GP	8.1	Both anxiety and depression	13.5
Covid-19 changed management	62.2	Other long-standing illness	32.4

*% unless otherwise stated

Cluster G – Access to healthcare acceptable and understand health information well if provided but managing health is not a priority

Cluster G is the largest cluster among all clusters, representing 18.2% of the sample. People in this cluster seem to have an acceptable relationship with their healthcare providers but managing their health may not always be a priority. They do not always use digital services and likely need better access to health information. The largest age group for this cluster is 46 – 60 years (31.0%) with about 40% having a university education, and over a quarter (28.5%) living in regional or remote areas. Over half (57.0%) were diagnosed 10 or more years ago. Close to 40% of the people in this cluster have their condition managed by public health services. Most people have generally good IBD knowledge but over a third (36.7%) are not sure about how IBD could cause other health problems.

Cluster G Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.67	3.09	2.87	2.86	2.91	2.82	3.82	3.70	3.86	4.03

Cluster G Demographics (n = 158)

Characteristics	%*	Characteristics	%*
% of sample	18.2	Medication:	
Mean age: Year (SD)	49.7 (16.5)	Taking 1 Aminosalicylates	35.4
Female	57.0	Taking 1 Corticosteroids	8.2
Lived alone	13.9	Taking 1 Immunomodulators	39.9
Lived in inner regional area	21.5	Taking 1 Biological agents	46.8
Lived in outer regional/remote area	7.0	Taking 1 Antibiotics	0.6
University undergraduate	25.3	Taking 1 Opioids/analgesics	3.2
University postgraduate	15.8	Taking 1 Psychotropics	3.8
Working full time	42.4	Taking other medication	38.0
Retired	24.7	Average number of medication types (SD)	2.8 (2.9)
Owned private insurance	69.6	No or little confident about:	
Owned healthcare card	33.5	Daily treatment	12.0
Diagnosed Crohn's disease	65.8	Plan of action	20.3
Diagnosed Ulcerative colitis	32.9	How diet affects	26.6
Diagnosed 10 or more years	57.0	Other health problems	36.7
Undergone IBD surgery	38.0	How feeling can affect	20.3
IBD constantly active	8.9	Perceived health poor to very poor	5.7
IBD often active	12.7	Perceived health fair	26.6
IBD sometimes active	15.2	No long-standing illness other than IBD	29.7
IBD occasionally active	14.6	Arthritis	33.5
IBD rarely active	17.1	Backpain	18.4
IBD remission	31.0	Diabetes	6.3

Cluster G Demographics (cont'd)

Characteristics	%*	Characteristics	%*
Managed by:		Heart problem	14.6
Public outpatient clinic	10.1	Lung problem	10.1
Public IBD specific outpatient clinic	27.2	Anxiety	18.4
Private specialist	46.8	Depression	13.3
GP	9.5	Both anxiety and depression	8.9
Covid-19 changed management	49.4	Other long-standing illness	19.0

*% unless otherwise stated

Cluster H – Finding the right healthcare can be challenging with inadequate social support and access to health information

Cluster H accounts for 9.9% of the sample. People in this cluster are likely to have a regular healthcare provider but communication may not be adequate to get them the right healthcare that is needed. There is also inadequate support from their social network. They are not motivated to use digital services and do not have good access to health information. This is the cluster with the second largest proportion of people aged 71 or above (16.3%), and also with the lowest proportion of people with university education (29.0%) among all clusters. Almost a quarter (23.3%) live alone and about 30% live in regional or remote areas. This is the cluster with the highest proportion of people diagnosed with IBD 10 or more years ago (76.7%). Over a quarter (26.7%) are in remission and about 30% are managed through public health services. Similar to other clusters, over a third of the people do not understand how IBD can cause other health problems. About a quarter experience either anxiety (26.7%) or depression (23.3%).

Cluster H Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.19	3.17	2.78	2.93	2.58	2.51	3.62	3.47	3.36	3.83

Cluster H Demographics (n = 86)

Characteristics	%*	Characteristics	%*
% of sample	9.9	Medication:	
Mean age: Year (SD)	52.1 (16.8)	Taking 1 Aminosalicylates	47.7
Female	69.8	Taking 1 Corticosteroids	16.3
Lived alone	23.3	Taking 1 Immunomodulators	30.2
Lived in inner regional area	24.4	Taking 1 Biological agents	38.4
Lived in outer regional/remote area	5.8	Taking 1 Antibiotics	2.3
University undergraduate	17.4	Taking 1 Opioids/analgesics	3.5
University postgraduate	11.6	Taking 1 Psychotropics	5.8
Working full time	33.7	Taking other medication	34.9
Retired	24.4	Average number of medication types (SD)	3.0 (3.1)
Owned private insurance	70.9	No or little confident about:	
Owned healthcare card	44.2	Daily treatment	16.3
Diagnosed Crohn’s disease	51.2	Plan of action	31.4
Diagnosed Ulcerative colitis	44.2	How diet affects	25.6
Diagnosed 10 or more years	76.7	Other health problems	46.5
Undergone IBD surgery	34.9	How feeling can affect	23.3
IBD constantly active	11.6	Perceived health poor to very poor	8.1
IBD often active	15.1	Perceived health fair	29.1
IBD sometimes active	15.1	No long-standing illness other than IBD	22.1
IBD occasionally active	15.1	Arthritis	32.6
IBD rarely active	16.3	Backpain	27.9

Cluster H Demographics (cont'd)

Characteristics	%*	Characteristics	%*
IBD remission	26.7	Diabetes	8.1
Managed by:		Heart problem	14.0
Public outpatient clinic	7.0	Lung problem	8.1
Public IBD specific outpatient clinic	23.3	Anxiety	26.7
Private specialist	46.5	Depression	23.3
GP	14.0	Both anxiety and depression	18.6
Covid-19 changed management	47.7	Other long-standing illness	22.1

*% unless otherwise stated

Cluster I – Inadequate information and services support but attempt to take control of own health

Representing 12.6% of the sample, people of cluster I sometimes find it difficult to engage with healthcare providers and cannot always get the care they need. Finding and using health information is another challenge. However, they attempt to manage their health and think digital technology may sometimes be useful for health. This is the youngest cluster, with the largest age group being 26 – 40 years old (38.5%). About half (52.3%) were diagnosed 10 or more years ago but there is also 26.6% who were diagnosed 1 to 4 years ago. This is the cluster with the second highest proportion of people (17.4%) experiencing constantly active IBD symptoms and only 16.5% are in remission. At least a third indicate they have limited knowledge about IBD. Arthritis (33.0%), anxiety (39.4%) and depression (25.7%) are other health concerns affecting many people in this cluster, and 11% of people take psychotropics medication as well as IBD medications.

Cluster I Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.82	3.06	2.47	3.17	2.70	2.75	3.16	3.00	3.26	3.58

Cluster I Demographics (n = 109)

Characteristics	%*	Characteristics	%*
% of sample	12.6	Medication:	
Mean age: Year (SD)	44.4 (17.9)	Taking 1 Aminosalicylates	35.8
Female	68.8	Taking 1 Corticosteroids	11.0
Lived alone	9.2	Taking 1 Immunomodulators	37.6
Lived in inner regional area	26.6	Taking 1 Biological agents	37.6
Lived in outer regional/remote area	5.5	Taking 1 Antibiotics	0.9
University undergraduate	35.8	Taking 1 Opioids/analgesics	4.6
University postgraduate	12.8	Taking 1 Psychotropics	11.0
Working full time	32.1	Taking other medication	42.2
Retired	19.3	Average number of medication types (SD)	2.7 (2.4)
Owned private insurance	60.6	No or little confident about:	
Owned healthcare card	41.3	Daily treatment	45.0
Diagnosed Crohn's disease	63.3	Plan of action	55.0
Diagnosed Ulcerative colitis	35.8	How diet affects	37.6
Diagnosed 10 or more years	52.3	Other health problems	69.7
Undergone IBD surgery	34.9	How feeling can affect	38.5
IBD constantly active	17.4	Perceived health poor to very poor	19.3
IBD often active	13.8	Perceived health fair	33.0
IBD sometimes active	22.0	No long-standing illness other than IBD	22.0
IBD occasionally active	14.7	Arthritis	33.0
IBD rarely active	17.4	Backpain	24.8
IBD remission	16.5	Diabetes	6.4

Cluster I Demographics (cont'd)

Characteristics	%*	Characteristics	%*
Managed by:		Heart problem	16.5
Public outpatient clinic	11.0	Lung problem	11.9
Public IBD specific outpatient clinic	21.1	Anxiety	39.4
Private specialist	46.8	Depression	25.7
GP	12.8	Both anxiety and depression	22.0
Covid-19 changed management	67.0	Other long-standing illness	29.4

*% unless otherwise stated

Cluster J – Low healthcare, social and information support but understand information well

Cluster J accounts for 5.3% of the sample. People in this cluster have limited access to health information and services with low social support. However, they can understand information well if it is provided. They also attempt to manage their health and may sometimes use digital technology for health. This is the second youngest cluster with only 2.2% aged 71 or above, the lowest among all other clusters, and with the highest proportion of people with postgraduate education (26.1%). This is an active working group with only 8.7% of people retired, the lowest among all clusters. While all other clusters have more people diagnosed with Crohn's disease than ulcerative colitis, this cluster has more people with ulcerative colitis. This cluster has the highest proportion of people (13.0%) who were diagnosed less than one year ago and only 19.6% were diagnosed 10 or more years ago. This cluster also has the highest proportion of people (19.6%) experiencing constantly active IBD symptoms, with only 13.0% in remission. Most of them indicated no or little confidence about their understanding of IBD knowledge. The proportion of people who experience both anxiety and depression (30.4%) is the second highest among all clusters.

Cluster J Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.72	2.32	2.46	3.09	2.31	2.88	2.83	2.87	3.66	4.20

Cluster J Demographics (n = 46)

Characteristics	%*	Characteristics	%*
% of sample	5.3	Medication:	
Mean age: Year (SD)	45.2 (14.7)	Taking 1 Aminosalicylates	43.5
Female	73.9	Taking 1 Corticosteroids	17.4
Lived alone	15.2	Taking 1 Immunomodulators	39.1
Lived in inner regional area	19.6	Taking 1 Biological agents	39.1
Lived in outer regional/remote area	15.2	Taking 1 Antibiotics	0.0
University undergraduate	32.6	Taking 1 Opioids/analgesics	4.3
University postgraduate	26.1	Taking 1 Psychotropics	13.0
Working full time	52.2	Taking other medication	32.6
Retired	8.7	Average number of medication types (SD)	2.6 (2.1)
Owned private insurance	73.9	No or little confident about:	
Owned healthcare card	28.3	Daily treatment	37.0
Diagnosed Crohn's disease	43.5	Plan of action	45.7
Diagnosed Ulcerative colitis	47.8	How diet affects	47.8
Diagnosed 10 or more years	52.2	Other health problems	45.7
Undergone IBD surgery	19.6	How feeling can affect	28.3
IBD constantly active	19.6	Perceived health poor to very poor	28.3
IBD often active	17.4	Perceived health fair	37.0
IBD sometimes active	23.9	No long-standing illness other than IBD	21.7
IBD occasionally active	13.0	Arthritis	28.3

Cluster J Demographics (cont'd)

Characteristics	%*	Characteristics	%*
IBD rarely active	15.2	Backpain	28.3
IBD remission	13.0	Diabetes	6.5
Managed by:		Heart problem	8.7
Public outpatient clinic	6.5	Lung problem	6.5
Public IBD specific outpatient clinic	23.9	Anxiety	43.5
Private specialist	37.0	Depression	39.1
GP	13.0	Both anxiety and depression	30.4
Covid-19 changed management	56.5	Other long-standing illness	39.1

*% unless otherwise stated

Cluster K – Low healthcare, social and information support and do not use digital health

Cluster K is a small cluster representing 4.2% of the sample. People in this cluster may not have an engaging relationship with healthcare providers. Finding and using information is generally difficult and using technology may not be of interest. A predominately female cluster, the largest age group is 46 – 70 (33.3%) and this cluster also has the highest proportion of people having high school or below education (38.9%). This is a cluster with the lowest proportion of people born in Australia (72.2%), but still with English as the first language for all. Half of the people in this cluster were diagnosed 10 or more years ago and over a quarter of them (27.7%) used public healthcare. Only 5.6% of the people in this cluster were in remission, the lowest among all clusters, with over a third (36.1%) experience sometimes active IBD symptoms. At least half have little or no confidence that they know their daily treatment, plan of action, the effect of diet and how IBD could lead to other health problems. Arthritis (44.4%), back pain (33.3%), anxiety (38.9%) and depression (25.0%) affect many people and almost half take other medications as well as IBD medications.

Cluster K Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.12	2.80	2.13	2.91	2.16	2.57	2.95	2.67	2.99	3.53

Cluster K Demographics (n = 36)

Characteristics	%*	Characteristics	%*
% of sample	4.2	Medication:	
Mean age: Year (SD)	50.9 (16.4)	Taking 1 Aminosalicylates	36.1
Female	75.0	Taking 1 Corticosteroids	8.3
Lived alone	13.9	Taking 1 Immunomodulators	36.1
Lived in inner regional area	22.2	Taking 1 Biological agents	44.4
Lived in outer regional/remote area	11.1	Taking 1 Antibiotics	2.8
University undergraduate	19.4	Taking 1 Opioids/analgesics	5.6
University postgraduate	16.7	Taking 1 Psychotropics	8.3
Working full time	33.3	Taking other medication	47.2
Retired	25.0	Average number of medication types (SD)	3.0 (3.2)
Owned private insurance	69.4	No or little confident about:	
Owned healthcare card	38.9	Daily treatment	52.8
Diagnosed Crohn's disease	58.3	Plan of action	61.1
Diagnosed Ulcerative colitis	36.1	How diet affects	50.0
Diagnosed 10 or more years	50.0	Other health problems	55.6
Undergone IBD surgery	50.0	How feeling can affect	38.9
IBD constantly active	11.1	Perceived health poor to very poor	25.0
IBD often active	19.4	Perceived health fair	55.6
IBD sometimes active	36.1	No long-standing illness other than IBD	27.8
IBD occasionally active	16.7	Arthritis	44.4
IBD rarely active	11.1	Backpain	33.3

Cluster K Demographics (cont'd)

Characteristics	%*	Characteristics	%*
IBD remission	5.6	Diabetes	5.6
Managed by:		Heart problem	13.9
Public outpatient clinic	8.3	Lung problem	8.3
Public IBD specific outpatient clinic	19.4	Anxiety	38.9
Private specialist	50.0	Depression	25.0
GP	11.1	Both anxiety and depression	16.7
Covid-19 changed management	50.0	Other long-standing illness	33.3

*% unless otherwise stated

Cluster L – Unable to engage with healthcare services and lack of social support with limited understanding of health information

This is the second smallest cluster with low scores across all health literacy dimensions. People in this cluster have difficulties communicating with their healthcare providers and are not getting the healthcare they need, despite 61.1% having their condition managed by private specialists. They have little access to information and will have difficulty understanding the information. Mostly female, this cluster does not have any member aged 15 – 25 but the largest age group is 26 – 40 years, the highest proportion comparing to all other clusters. Cluster L also has the lowest proportion of people with a postgraduate qualification (5.6%) among all clusters but 38.9% of people have completed university, the highest among all clusters. 44.4% of people were diagnosed 10 or more years ago, the lowest among all clusters, while 27.8% were diagnosed 1 – 4 years ago. More than half indicate little or no confidence in their knowledge about IBD knowledge, especially for the plan of action when IBD gets bad (83.3%), the highest among all clusters. Cluster L also has the highest proportion of people who experience anxiety (44.4%) and depression (44.4%) with 33.3% having both anxiety and depression.

Cluster L Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.41	2.57	2.04	2.59	2.09	2.32	1.99	1.91	2.17	2.79

Cluster L Demographics

Characteristics	%*	Characteristics	%*
% of sample	2.1	Medication:	
Mean age: Year (SD)	48.2 (17.8)	Taking 1 Aminosalicylates	33.3
Female	72.2	Taking 1 Corticosteroids	5.6
Lived alone	5.6	Taking 1 Immunomodulators	38.9
Lived in inner regional area	27.8	Taking 1 Biological agents	44.4
Lived in outer regional/remote area	5.6	Taking 1 Antibiotics	0.0
University undergraduate	38.9	Taking 1 Opioids/analgesics	16.7
University postgraduate	5.6	Taking 1 Psychotropics	5.6
Working full time	38.9	Taking other medication	16.7
Retired	16.7	Average number of medication types (SD)	1.7 (1.3)
Owned private insurance	72.2	No or little confident about:	
Owned healthcare card	22.2	Daily treatment	66.7
Diagnosed Crohn's disease	66.7	Plan of action	83.3
Diagnosed Ulcerative colitis	33.3	How diet affects	55.6
Diagnosed 10 or more years	44.4	Other health problems	72.2
Undergone IBD surgery	16.7	How feeling can affect	27.8
IBD constantly active	16.7	Perceived health poor to very poor	38.9
IBD often active	0.0	Perceived health fair	33.3
IBD sometimes active	22.2	No long-standing illness other than IBD	16.7
IBD occasionally active	22.2	Arthritis	38.9

Cluster L Demographics (cont'd)

Characteristics	n (%)	Characteristics	n (%)
IBD rarely active	11.1	Backpain	33.3
IBD remission	27.8	Diabetes	5.6
Managed by:		Heart problem	5.6
Public outpatient clinic	5.6	Lung problem	11.1
Public IBD specific outpatient clinic	11.1	Anxiety	44.4
Private specialist	61.1	Depression	44.4
GP	22.2	Both anxiety and depression	33.3
Covid-19 changed management	55.6	Other long-standing illness	33.3

*% unless otherwise stated

Cluster M – Lack of healthcare, social and information support and but attempt to manage health

Cluster M is the smallest cluster, representing only 1% of the sample. People in this cluster do not have access to health information and services and they also lack social support. However, they do try to take control of their health and may understand information well when it is provided. People in this cluster are the oldest in comparison to other clusters with no one aged 15 – 25 and the largest age group is 46 – 70 (66.7%), the highest among all other clusters. There are 44.4% of them reside in outer regional or remote areas, the highest among all clusters. This cluster has the fewest people with private health insurance. About two thirds were diagnosed 10 or more years ago and 66.7% have had IBD surgery, the highest among all clusters. Management of IBD is mainly by GP (44.4%), the highest among all clusters, and no one used a private specialist. About a third are in remission but 44.4% often experience active IBD symptoms. There is also a considerable proportion of people who indicate they have limited understanding of most IBD knowledge. This cluster also has the highest proportion of people taking opioids/analgesics medication (33.3%).

Cluster M Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
1.20	2.08	1.47	2.96	1.51	2.20	2.33	2.20	2.38	3.76

Cluster M Demographics (n = 18)

Characteristics	%*	Characteristics	%*
% of sample	1.0	Medication:	
Mean age: Year (SD)	56.7 (11.1)	Taking 1 Aminosalicylates	22.2
Female	77.8	Taking 1 Corticosteroids	0.0
Lived alone	11.1	Taking 1 Immunomodulators	33.3
Lived in inner regional area	11.1	Taking 1 Biological agents	22.3
Lived in outer regional/remote area	44.4	Taking 1 Antibiotics	0.0
University undergraduate	33.3	Taking 1 Opioids/analgesics	33.3
University postgraduate	11.1	Taking 1 Psychotropics	11.1
Working full time	22.2	Taking other medication	55.6
Retired	11.1	Average number of medication types	3.3 (3.4)
Owned private insurance	55.6	No or little confident about:	
Owned healthcare card	55.6	Daily treatment	33.3
Diagnosed Crohn's disease	55.6	Plan of action	66.7
Diagnosed Ulcerative colitis	33.3	How diet affects	44.4
Diagnosed 10 or more years	66.7	Other health problems	66.7
Undergone IBD surgery	66.7	How feeling can affect	22.2
IBD constantly active	11.1	Perceived health poor to very poor	22.2
IBD often active	44.4	Perceived health fair	44.4
IBD sometimes active	0.0	No long-standing illness other than IBD	0.0
IBD occasionally active	0.0	Arthritis	44.4

Cluster M Demographics (cont'd)

Characteristics	%*	Characteristics	%*
IBD rarely active	11.1	Backpain	33.3
IBD remission	33.3	Diabetes	0.0
Managed by:		Heart problem	33.3
Public outpatient clinic	11.1	Lung problem	22.2
Public IBD specific outpatient clinic	22.2	Anxiety	44.4
Private specialist	0.0	Depression	22.2
GP	44.4	Both anxiety and depression	22.2
Covid-19 changed management	33.3	Other long-standing illness	44.4

*% unless otherwise stated

Appendix 2 – Clusters for Carers

Cluster	Number in clusters	Number in clusters (%)	eHLQ 5. Motivated to engage with digital services	1. Feeling understood and supported by health care providers	2. Having sufficient information to manage my health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability to actively engage with healthcare providers	7. Navigating the healthcare system	8. Ability to find good health information	9. Understand health information well enough to know what to do
			Score range: 1 (lowest)–4 (highest)						Score range: 1 (lowest)–5 (highest)			
A	2	2.4%	3.70	3.88	4.00	3.70	3.70	3.90	4.80	4.75	4.90	5.00
B	7	8.3%	2.97	3.86	3.36	3.31	3.23	3.31	4.34	3.98	3.97	4.17
C	8	9.5%	2.83	3.53	3.09	3.73	2.43	3.63	3.73	3.48	4.08	4.80
D	11	13.1%	2.76	3.14	3.02	3.05	3.07	2.65	3.91	3.79	3.87	3.96
E	6	7.1%	2.50	3.33	2.75	3.03	2.20	2.67	4.10	3.75	4.07	4.67
F	12	14.3%	2.65	3.15	2.71	2.70	2.72	3.15	3.80	3.60	3.87	4.00
G	6	7.1%	3.37	2.79	2.50	3.67	2.43	3.17	2.63	2.78	3.77	3.90
H	12	14.3%	2.25	3.08	2.79	3.00	2.58	2.68	3.55	3.11	3.20	3.77
I	7	8.3%	2.43	2.64	2.18	2.60	2.14	2.57	2.83	2.57	3.43	3.83
J	2	2.4%	1.60	2.63	1.38	3.80	1.20	3.20	2.40	2.67	3.50	4.20
K	10	11.9%	2.28	2.33	1.70	3.22	1.94	2.64	2.20	2.13	2.74	3.20
L	1	1.2%	3.20	1.00	1.25	3.60	1.20	2.80	1.20	1.33	4.20	3.80

Note: The scores are highlighted using the traffic light system of colour coding as recommended in the Ophelia process. Cells coloured in green represented higher scores, the range of yellow represents medium scores and red indicates lower scores.

Cluster	Number in clusters	Number in clusters (%)	Overall average score	Female (%)	Aged 26 - 55 (%)	Aged 56 - 91 (%)	Australian born (%)	Spoke English at home (%)	Household with two members (%)	Lived in major cities (%)	Lived in inner regional area (%)	Lived in outer regional or remote area (%)
A	2	2.4%	4.26	100.0%	-	-	-	-	-	-	-	-
B	7	8.3%	3.66	71.4%	71.4%	28.6%	57.1%	100.0%	28.6%	42.9%	42.9%	0.0%
C	8	9.5%	3.53	87.5%	87.5%	12.5%	100.0%	100.0%	12.5%	87.5%	12.5%	0.0%
D	11	13.1%	3.35	63.6%	63.6%	36.4%	72.7%	100.0%	18.2%	54.5%	27.3%	0.0%
E	6	7.1%	3.33	83.3%	83.3%	16.7%	83.3%	100.0%	16.7%	100.0%	0.0%	0.0%
F	12	14.3%	3.25	100.0%	58.3%	41.7%	91.7%	100.0%	16.7%	75.0%	16.7%	8.3%
G	6	7.1%	3.11	83.3%	100.0%	0.0%	83.3%	100.0%	16.7%	66.7%	16.7%	16.7%
H	12	14.3%	3.01	83.3%	41.7%	58.3%	75.0%	100.0%	33.3%	83.3%	16.7%	0.0%
I	7	8.3%	2.74	57.1%	85.7%	14.3%	85.7%	100.0%	28.6%	57.1%	28.6%	14.3%
J	2	2.4%	2.68	100.0%	-	-	-	-	-	-	-	-
K	10	11.9%	2.45	100.0%	40.0%	60.0%	80.0%	100.0%	10.0%	50.0%	10.0%	40.0%
L	1	1.2%	2.39	100.0%	-	-	-	-	-	-	-	-

Cluster	Number in clusters	High school or below (%)	Trade/Certificate/Diploma (%)	University undergraduate (%)	University postgraduate (%)	Working full time (%)	Working part time (%)	Retired (%)	Owned private insurance (%)	Owned healthcare card (%)	Perceived health of person cared poor to very poor (%)	Perceived health of person cared fair (%)
A	2	-	-	-	-	-	-	-	-	-	-	-
B	7	14.3%	0.0%	14.3%	71.4%	14.3%	42.9%	14.3%	100.0%	0.0%	0.0%	28.6%
C	8	0.0%	37.5%	37.5%	25.0%	37.5%	37.5%	0.0%	100.0%	12.5%	25.0%	12.5%
D	11	9.1%	54.5%	27.3%	0.0%	36.4%	27.3%	18.2%	72.7%	45.5%	0.0%	0.0%
E	6	16.7%	16.7%	0.0%	66.7%	50.0%	16.7%	0.0%	66.7%	33.3%	16.7%	16.7%
F	12	8.3%	16.7%	58.3%	16.7%	41.7%	50.0%	0.0%	83.3%	25.0%	8.3%	0.0%
G	6	0.0%	50.0%	16.7%	33.3%	33.3%	33.3%	0.0%	50.0%	16.7%	16.7%	33.3%
H	12	16.7%	41.7%	16.7%	25.0%	41.7%	16.7%	25.0%	83.3%	16.7%	25.0%	16.7%
I	7	14.3%	42.9%	42.9%	0.0%	57.1%	0.0%	0.0%	57.1%	28.6%	14.3%	57.1%
J	2	-	-	-	-	-	-	-	-	-	-	-
K	10	10.0%	20.0%	60.0%	10.0%	40.0%	20.0%	30.0%	80.0%	20.0%	40.0%	40.0%
L	1	-	-	-	-	-	-	-	-	-	-	-

Cluster	Number in clusters	No or little confident about daily treatment (%)	No or little confident about plan of action (%)	No or little confident about how diet affects (%)	No or little confident about other health problems (%)	No or little confident about how feeling can affect (%)	Managed by public outpatient clinic	Managed by public IBD specific outpatient clinic (%)	Managed by private specialist (%)	Managed by GP (%)	Covid-19 changed way of management (%)
A	2	-	-	-	-	-	-	-	-	-	-
B	7	0.0%	28.6%	28.6%	28.6%	14.3%	0.0%	28.6%	57.1%	14.3%	85.7%
C	8	12.5%	12.5%	37.5%	12.5%	12.5%	12.5%	50.0%	37.5%	0.0%	50.0%
D	11	0.0%	27.3%	45.5%	18.2%	18.2%	27.3%	45.5%	27.3%	0.0%	63.6%
E	6	0.0%	50.0%	33.3%	50.0%	33.3%	0.0%	16.7%	50.0%	0.0%	66.7%
F	12	16.7%	25.0%	41.7%	33.3%	33.3%	33.3%	33.3%	25.0%	0.0%	50.0%
G	6	66.7%	66.7%	50.0%	50.0%	33.3%	16.7%	33.3%	33.3%	16.7%	100.0%
H	12	33.3%	33.3%	58.3%	41.7%	25.0%	16.7%	8.3%	75.0%	0.0%	41.7%
I	7	57.1%	71.4%	57.1%	57.1%	28.6%	14.3%	28.6%	57.1%	0.0%	71.4%
J	2	-	-	-	-	-	-	-	-	-	-
K	10	90.0%	90.0%	70.0%	70.0%	50.0%	0.0%	50.0%	20.0%	10.0%	70.0%
L	1	-	-	-	-	-	-	-	-	-	-

Cluster	Number in clusters	No long-standing illness (%)	Presence of some form of long-standing illness (%)	Presence of mental health condition* (%)
A	2	-	-	-
B	7	42.9%	57.1%	0.0%
C	8	75.0%	25.0%	12.5%
D	11	45.5%	36.4%	0.0%
E	6	33.3%	66.7%	66.7%
F	12	50.0%	25.0%	8.3%
G	6	66.7%	33.3%	16.7%
H	12	33.3%	58.3%	16.7%
I	7	42.9%	42.9%	28.6%
J	2	-	-	-
K	10	40.0%	60.0%	10.0%
L	1	-	-	-

*Includes anxiety, depression and bi-polar.

Cluster A – Confident in using health information and services and well-supported

This is a small cluster with only two members (2.4% of the sample) with almost perfect scores across all scales. Demographics not linked due to the small sample size and vignette will not be developed for this cluster.

Cluster A Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
3.70	3.88	4.00	3.70	3.70	3.90	4.80	4.75	4.90	5.00

Cluster B – Comfortable in using health information and services with good support

Cluster B, representing 8.3% of the sample, is another cluster with scores on the higher end of the score range across all scales even though they are all lower than Cluster A. Nevertheless, they are getting very good support from healthcare providers, the same as Cluster A. This cluster is older than Cluster A and most (71.4%) have postgraduate qualifications. Over half of the people in this cluster (57.1%) have some form of chronic health condition but no mental health issues. Close to half (42.7%) live in an inner regional area. The management of the IBD condition of the person they cared for is mainly from private specialists. Most of them have good IBD knowledge and they consider the person they care for has generally good health.

Cluster B Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.97	3.86	3.36	3.31	3.23	3.31	4.34	3.98	3.97	4.17

Cluster B Demographics (n = 7)

Characteristics	%*	Characteristics	%*
% of sample	8.3	No or little confident about:	
Mean age: Year (SD)	54.7 (5.8)	Daily treatment	0.0
Female	71.4	Plan of action	28.6
Household with two members	28.6	How diet affects	28.6
Lived in inner regional area	42.9	Other health problems	28.6
Lived in outer regional or remote area	0.0	How feeling can affect	14.3
University undergraduate	14.3	Person cared for managed by:	
University postgraduate	71.4	Public outpatient clinic	0.0
Working full time	14.3	Public IBD specific outpatient clinic	28.6
Retired	14.3	Private specialist	57.1
No long-standing illness	42.9	GP	14.3
Reported long-standing illness^	57.1	Perceived health of person cared for:	
Reported mental health condition#	0.0	Poor to very poor	0.0
Owned private insurance	100.0	Fair	28.6
Owned healthcare card	0.0	Covid-19 changed way of management	85.7

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster C – Good understanding of health information but may not always get the right kind of care and inadequate social support

Cluster C accounts for 9.5% of the sample. People in this cluster show good understanding of health information. They generally have good healthcare support but getting the right kind of healthcare for the person they care for can sometimes be challenging. They have inadequate social support and find digital health services not always useful. They are younger than Cluster B and over half of them have university or above education, while most reside in metropolitan areas. Three quarters (75%) report having no chronic health issues. They generally express good understanding of IBD knowledge except for how diet could affect the condition. The management of IBD for the person they care for is mostly by public IBD outpatient clinic or private specialists. A quarter of them perceive the health of the person they care for as poor or very poor.

Cluster C Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.83	3.53	3.09	3.73	2.43	3.63	3.73	3.48	4.08	4.80

Cluster C Demographics (n = 8)

Characteristics	%*	Characteristics	%*
% of sample	9.5	No or little confident about:	
Mean age: Year (SD)	45.8 (7.7)	Daily treatment	12.5
Female	87.5	Plan of action	12.5
Household with two members	12.5	How diet affects	37.5
Lived in inner regional area	12.5	Other health problems	12.5
Lived in outer regional or remote area	0.0	How feeling can affect	12.5
University undergraduate	37.5	Person cared for managed by:	
University postgraduate	25.0	Public outpatient clinic	12.5
Working full time	37.5	Public IBD specific outpatient clinic	50.0
Retired	0.0	Private specialist	37.5
No long-standing illness	75.0	GP	0.0
Reported long-standing illness^	25.0	Perceived health of person cared for:	
Reported mental health condition#	12.5	Poor to very poor	25.0
Owned private insurance	100.0	Fair	12.5
Owned healthcare card	12.5	Covid-19 changed way of management	50.0

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster D – Have intermittent healthcare support while appraising information can be challenging

Cluster D is the second largest cluster among all clusters (13.1% of the sample). Their relationship with their healthcare providers is likely to be intermittent. They may not always have good access to health information and they could get confused when they come across conflicting information. About a third are male and aged over 56. This is the cluster with the least number of people having university or above education (27.3%). Over a third have some form of chronic health condition but none experience mental health issues. Their IBD knowledge is generally good except for how diet might impact the condition. Over a quarter (27.3%) of the people cared for have their condition managed by public outpatient clinic and all carers perceive the health status of the person they care for as good to excellent.

Cluster D Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.76	3.14	3.02	3.05	3.07	2.65	3.91	3.79	3.87	3.96

Cluster D Demographics (n = 11)

Characteristics	%*	Characteristics	%*
% of sample	13.1	No or little confident about:	
Mean age: Year (SD)	52.1 (11.8)	Daily treatment	0.0
Female	63.6	Plan of action	27.3
Household with two members	18.2	How diet affects	45.5
Lived in inner regional area	27.3	Other health problems	18.2
Lived in outer regional or remote area	0.0	How feeling can affect	18.2
University undergraduate	27.3	Person cared for managed by:	
University postgraduate	0.0	Public outpatient clinic	27.3
Working full time	36.4	Public IBD specific outpatient clinic	45.5
Retired	18.2	Private specialist	27.3
No long-standing illness	45.5	GP	0.0
Reported long-standing illness^	36.4	Perceived health of person cared for:	
Reported mental health condition#	0.0	Poor to very poor	0.0
Owned private insurance	72.7	Fair	0.0
Owned healthcare card	45.5	Covid-19 changed way of management	63.6

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster E – Limited social support and may not always have access to good information

Representing 7.1% of the sample, people in Cluster E experience limited social support and they don't usually use digital health services. While they do have good healthcare support, finding the right healthcare can present challenges. They find conflicting health information confusing but if they are provided with good information, they will understand it reasonably well. Most of the people in this cluster are aged below 55 and they all live in metropolitan areas. Two thirds (66.7%) have postgraduate qualifications, the second largest proportion among all clusters, and half are working full time. About two thirds experience some form of mental health issue, such as anxiety or depression. About half are not sure about the plan of action if their IBD gets bad and how IBD could lead to other health problems. None of the people they care have their IBD condition managed by public outpatient clinics and most consider the health status of the person they care for as good to excellent.

Cluster E Scores

Score range: 1 (lowest) – 4 (highest)						Score range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.50	3.33	2.75	3.03	2.20	2.67	4.10	3.75	4.07	4.67

Cluster E Demographics (n = 6)

Characteristics	%*	Characteristics	%*
% of sample	7.1	No or little confident about:	
Mean age: Year (SD)	43.7 (10.8)	Daily treatment	0.0
Female	83.3	Plan of action	50.0
Household with two members	16.7	How diet affects	33.3
Lived in inner regional area	0.0	Other health problems	50.0
Lived in outer regional or remote area	0.0	How feeling can affect	33.3
University undergraduate	0.0	Person cared for managed by:	
University postgraduate	66.7	Public outpatient clinic	0.0
Working full time	50.0	Public IBD specific outpatient clinic	16.7
Retired	0.0	Private specialist	50.0
No long-standing illness	33.3	GP	0.0
Reported long-standing illness^	66.7	Perceived health of person cared for:	
Reported mental health condition#	66.7	Poor to very poor	16.7
Owned private insurance	66.7	Fair	16.7
Owned healthcare card	33.3	Covid-19 changed way of management	66.7

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster F – Some support to health information and services and generally leave health in professional hands

Cluster F is one of the largest clusters, accounting for 14.3% of the sample. People in this cluster generally have support from healthcare providers and are willing to leave the management of the health of the person they care for in the hands of the healthcare provider. However, they may not always know what healthcare is available, and may have poor social support. Getting health information can be difficult sometimes but they generally understand information well. They do not usually rely on digital health services. This is another cluster with only females, the same as Cluster A, but people in this cluster are older, with 41.7% aged over 56. People in this cluster are better educated and none of them are retired. Only a quarter report having some form of chronic health condition. They generally have good knowledge about IBD except how diet could affect the condition. About a third (33.3%) of the people they care for have their condition managed by public outpatient clinic. They generally considered the health of the person they cared for good to excellent.

Cluster F Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.65	3.15	2.71	2.70	2.72	3.15	3.80	3.60	3.87	4.00

Cluster F Demographics (n = 12)

Characteristics	%*	Characteristics	%*
% of sample	14.3	No or little confident about:	
Mean age: Year (SD)	52.7 (6.8)	Daily treatment	16.7
Female	100.0	Plan of action	25.0
Household with two members	16.7	How diet affects	41.7
Lived in inner regional area	16.7	Other health problems	33.3
Lived in outer regional or remote area	8.3	How feeling can affect	33.3
University undergraduate	58.3	Person cared for managed by:	
University postgraduate	16.7	Public outpatient clinic	33.3
Working full time	41.7	Public IBD specific outpatient clinic	33.3
Retired	0.0	Private specialist	25.0
No long-standing illness	50.0	GP	0.0
Reported long-standing illness^	25.0	Perceived health of person cared for:	
Reported mental health condition#	8.3	Poor to very poor	8.3
Owned private insurance	83.3	Fair	0.0
Owned healthcare card	25.0	Covid-19 changed way of management	50.0

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster G – Inadequate healthcare and social support and likely to be managing health independently

Cluster G, 7.1% of the sample, may not have an engaging relationship with their healthcare providers and getting the right care can be at times difficult. As such, they need to rely on their own resources to find good health information and they believe digital services are useful for health. They see that it is important that they take control of the health of the person they care for, with scores for Scale 3 Actively managing my health being the third highest among all clusters. People in this cluster are aged less than 55 years, are better educated, and a third live in regional or remote areas. Half of the people in this is cluster have private health insurance. They are generally healthy with two thirds (66.7%) reporting no chronic health condition. About a third of the people they care for have their condition managed by public outpatient clinic or their GPs. People in this cluster seem not to have much confidence in their understanding of IBD conditions and half perceive the health status of the person they care as fair or poor.

Cluster G Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
3.37	2.79	2.50	3.67	2.43	3.17	2.63	2.78	3.77	3.90

Cluster G Demographics (n = 6)

Characteristics	%*	Characteristics	%*
% of sample	7.1	No or little confident about:	
Mean age: Year (SD)	43.2 (9.7)	Daily treatment	66.7
Female	83.3	Plan of action	66.7
Household with two members	16.7	How diet affects	50.0
Lived in inner regional area	16.7	Other health problems	50.0
Lived in outer regional or remote area	16.7	How feeling can affect	33.3
University undergraduate	16.7	Person cared for managed by:	
University postgraduate	33.3	Public outpatient clinic	16.7
Working full time	33.3	Public IBD specific outpatient clinic	33.3
Retired	0.0	Private specialist	33.3
No long-standing illness	66.7	GP	16.7
Reported long-standing illness^	33.3	Perceived health of person cared for:	
Reported mental health condition#	16.7	Poor to very poor	16.7
Owned private insurance	50.0	Fair	33.3
Owned healthcare card	16.7	Covid-19 changed way of management	100.0

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster H – Inadequate healthcare and social support but attempt to take control of the health of the person they cared for

Cluster H is the other largest cluster (as Cluster F), representing 14.3% of the sample. They are likely to have a regular healthcare provider, given 75% of people they care for have their condition managed by private specialist, but they may have difficulties sharing their concerns with their provider. There is likely to be limited support from their social networks. Finding health information and using it is another challenge and they don't usually use digital services. Over half of the people in this cluster are aged 56 or older and a quarter of them are retired. About a third live only with the person they care for and two thirds of them also have to manage their own chronic health conditions, as well as being a carer. Many of them are not sure about how diet could affect IBD and a quarter perceived the health of the person they care for as poor to very poor.

Cluster H Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.25	3.08	2.79	3.00	2.58	2.68	3.55	3.11	3.20	3.77

Cluster H Demographics (n = 12)

Characteristics	%*	Characteristics	%*
% of sample	14.3	No or little confident about:	
Mean age: Year (SD)	59.8 (9.5)	Daily treatment	33.3
Female	83.3	Plan of action	33.3
Household with two members	33.3	How diet affects	58.3
Lived in inner regional area	16.7	Other health problems	41.7
Lived in outer regional or remote area	0.0	How feeling can affect	25.0
University undergraduate	16.7	Person cared for managed by:	
University postgraduate	25.0	Public outpatient clinic	16.7
Working full time	41.7	Public IBD specific outpatient clinic	8.3
Retired	25.0	Private specialist	75.0
No long-standing illness	33.3	GP	0.0
Reported long-standing illness^	58.3	Perceived health of person cared for:	
Reported mental health condition#	16.7	Poor to very poor	25.0
Owned private insurance	83.3	Fair	16.7
Owned healthcare card	16.7	Covid-19 changed way of management	41.7

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster I – Limited relationship with healthcare providers and limited access and understanding of health information with also low social support

Cluster I consists of 8.3% of the sample. People in this cluster do not have an engaging relationship with their healthcare provider, even though 57.1% of the people they care for have their conditions managed by private specialists. They are likely to have difficulty in getting the kind of care that they need, but they seem to be leaving the management of the person they care for mostly to their healthcare providers. Their access and use of health information is limited while digital services are generally not used. This is the cluster with the highest proportion of males and most of them are under 55 years. No one in this cluster has a postgraduate qualification but there are 42.9% who have completed university and 57.1% who work full time. Over a quarter experience some mental health issues, such as anxiety or depression. Most are not sure about the daily treatment, plan of action, how diet affects IBD and that IBD could lead to other health problems. Over two thirds (71.4%) rated the health of the person they cared for as just fair or even poor.

Cluster I Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.43	2.64	2.18	2.60	2.14	2.57	2.83	2.57	3.43	3.83

Cluster I Demographics (n = 7)

Characteristics	%*	Characteristics	%*
% of sample	8.3	No or little confident about:	
Mean age: Year (SD)	41.7 (11.9)	Daily treatment	57.1
Female	57.1	Plan of action	71.4
Household with two members	28.6	How diet affects	57.1
Lived in inner regional area	28.6	Other health problems	57.1
Lived in outer regional or remote area	14.3	How feeling can affect	28.6
University undergraduate	42.9	Person cared for managed by:	
University postgraduate	0.0	Public outpatient clinic	14.3
Working full time	57.1	Public IBD specific outpatient clinic	28.6
Retired	0.0	Private specialist	57.1
No long-standing illness	42.9	GP	0.0
Reported long-standing illness^	42.9	Perceived health of person cared for:	
Reported mental health condition#	28.6	Poor to very poor	14.3
Owned private insurance	57.1	Fair	57.1
Owned healthcare card	28.6	Covid-19 changed way of management	71.4

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster J – Lack of access to health information and very low healthcare and social support but actively managing health of the person they cared for

This is another small cluster like Cluster A with only two members. People in this cluster do not use technology for health and has the lowest eHLQ scale Motivated to engage with digital services score among all clusters. They also have one of the lowest scores for Scale 4 Social support for health, same as Cluster L. They have limited healthcare support and do not have adequate health information. However, they are likely to be able to act on information if available. This is another cluster, like Cluster G, which has members who are willing to take control of the health of the person they cared for, despite the lack of support. Demographics not linked due to the small sample size and vignette will not be developed for this cluster.

Cluster J Scores

Score Range: 1 (lowest) – 4 (highest)						Score Range: 1 (lowest) – 5 (highest)			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
1.60	2.63	1.38	3.80	1.20	3.20	2.40	2.67	3.50	4.20

Cluster K – Limited access and understanding of health information with limited support but are thinking about health

Cluster K accounts for 11.9% of the sample and people in this cluster generally have lower scores across all scales except for Scale 3 Actively managing my health. They have limited healthcare and social support and also limited access and understanding about health information. They do not see the value of digital technology for health, but they do take responsibility of the health of the person they cared for. This is another all-female cluster with 60% aged 56 or over and 40.0% who live in outer regional or remote areas. This cluster, among all clusters, has the highest proportion of people who are retired (30%). Despite 70% of the people in this cluster having a university education, most have no or little confidence about IBD knowledge. Most (80%) perceive the health status of the person they care for as being fair or poor to very poor.

Cluster K Scores

Score Range: 1 - 4						Score Range: 1 - 5			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
2.28	2.33	1.70	3.22	1.94	2.64	2.20	2.13	2.74	3.20

Cluster K Demographics (n = 10)

Characteristics	%*	Characteristics	%*
% of sample	11.9	No or little confident about:	
Mean age: Year (SD)	58.9 (13.9)	Daily treatment	90.0
Female	100.0	Plan of action	90.0
Household with two members	10.0	How diet affects	70.0
Lived in inner regional area	10.0	Other health problems	70.0
Lived in outer regional or remote area	40.0	How feeling can affect	50.0
University undergraduate	60.0	Person cared for managed by:	
University postgraduate	10.0	Public outpatient clinic	0.0
Working full time	40.0	Public IBD specific outpatient clinic	50.0
Retired	30.0	Private specialist	20.0
No long-standing illness	40.0	GP	10.0
Reported long-standing illness^	60.0	Perceived health of person cared for:	
Reported mental health condition#	10.0	Poor to very poor	40.0
Owned private insurance	80.0	Fair	40.0
Owned healthcare card	20.0	Covid-19 changed way of management	70.0

*% unless otherwise stated

^Includes arthritis, back pain, heart problems, lung problems, cancer, diabetes, kidney problems or other.

#Includes anxiety, depression and bi-polar.

Cluster L – Low healthcare and social support but good access and understanding of health information while also actively managing health

Cluster L is a single-member cluster that displays a very different health literacy pattern to the other clusters. This person has very low healthcare and social support. Even though the person rated highly on the skill of finding and understanding information, this person did not see information as sufficient. However, digital resources are considered useful and they are likely to be managing the health of the person cared for independently. Demographics not linked due to the small sample size and vignette will not be developed for this cluster.

Cluster L Scores

Score Range: 1 - 4						Score Range: 1 - 5			
eHLQ 5	HLQ 1	HLQ 2	HLQ 3	HLQ 4	HLQ 5	HLQ 6	HLQ 7	HLQ 8	HLQ 9
Motivated to engage with digital services	Feeling understood and supported by health care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with healthcare providers	Navigating the healthcare system	Ability to find good health information	Understand health information well enough to know what to do
3.20	1.00	1.25	3.60	1.20	2.80	1.20	1.33	4.20	3.80

Appendix 3 – Manuscript for protocol paper

See next page.

Centre for Global Health and Equity

Crohn's & Colitis Australia

Ophelia Phase 1 – Progress report 2

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Tuesday, 2 June 2021

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Centre for Global Health and Equity
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CCA Ophelia Phase 1 – Progress Report 2

Introduction

The following activities take place in Ophelia Phase 1: needs assessment (quantitative and qualitative data collection and analysis); development of vignettes to represent local health literacy profiles; the ideas generation consultation (workshops, online activities); analysis and presentation of the ideas generated. Phase 2 involves the selection and prioritisation of ideas then development and testing of actions ready for implementation in Phase 3.

Progress Report 1 (delivered on 16 December 2020) described the needs assessment data collection and analysis (descriptive statistics, cluster analysis), a description of vignette development (including an example vignette), and the ideas generation workshop process.

This Progress Report 2 presents the 8 vignettes that were developed for the ideas generation consultation, describes the participants who took part in ideas generation consultations, and presents the list of ideas generated by participants.

1. The 8 vignettes

As described in Progress Report 1, the vignettes are based on the data collected during the needs assessment and serve the purpose of guiding the discussions in workshops to generate ideas for how to improve information and services for people with IBD. The vignettes are based on the cluster analysis and demographic data. There were 8 vignettes developed for this project, each one describing a fictional yet evidence-based person. The vignettes are listed below from people who experience fewer health literacy challenges through to people who experience more health literacy challenges.

Vignette 1: Cluster B – Sarah

Sarah is 43, lives in Sydney and is an academic at a large university. She was born in England but was diagnosed with ulcerative colitis 9 years ago after moving to Sydney for work. Her specialist prescribed Salofalk and that has worked well for her. She still sees this specialist. She has now been in remission for 5 years. Sarah attends an IBD support group where she has made friends.

Sarah tends to get anxious, especially about work and health, but knows that if she gets upset or stressed it triggers her colitis symptoms and so she exercises and meditates daily to manage her emotions. She thinks her health is only ok even though she's doing quite well.

Vignette 2: Cluster C/D – Frank

Frank is 67 and lives in a main city with his wife. He retired from the public service 2 years ago. He was diagnosed with Crohn's disease when he was 25 after getting so sick he was crawling on the floor to get to bed. The doctors said he'd been close to dying. They cut some of his bowel out, which helped a lot but didn't stop all the symptoms all the time. Interestingly, his symptoms seem much better since he retired.

Frank stays at home a lot now and doesn't have many friends, especially not friends who he can talk to about his health. When he has the occasional bad turn with his Crohn's, Frank goes to the IBD clinic at the public hospital where he can get the care and information he needs. Some of the information he has read has made him worry about how he will cope with and manage flare ups as he gets older. Frank has tried to find information online about his prognosis but found it more confusing than helpful.

Vignette 3: Cluster F – Emily

Emily is 19 and was diagnosed 4 years ago with ulcerative colitis. She often couldn't go to school because of the symptoms and she stopped doing sport and going out with friends for fear of embarrassing herself. Emily managed to get a job as a computer programmer. Working online from home because of the pandemic works well for her. She lives with her parents and younger brother but feels they don't understand what she is going through. She is angry about how much the colitis has changed the life she thought she would be living now.

Emily takes the medication prescribed by her specialist – it seems to help. She finds the advice from doctors too general and demanding and she feels they don't listen to her. She prefers to look at what other young people are saying online. Although sometimes active, Emily's colitis hasn't been too bad for about 6 months, but she is still being careful about her diet.

Vignette 4: Cluster H – George

George is 72 and has worked as a mechanic in rural QLD all his life. He was diagnosed in 1974 with ulcerative colitis, which terrified him because he didn't know what it was, he didn't know anyone else with it, and it wasn't the sort of thing he could talk about with his mates. It took a long time to get his medication right. He avoided romantic relationships for years and lost contact with a few people.

George did eventually get married. His wife is his main support and she helps him drive the 4 hours to his specialist in a regional town centre. They stay overnight especially if he has a procedure. As well as his colitis medication, he takes depression medication and his specialist suggested he talk to a psychologist, but George didn't think that was for him. He also doesn't want to talk to people on a computer, so he is also not interested in joining an online support group.

Vignette 5: Cluster I – Nick

Nick is 23 and finished university last year. He is still living with his parents in a regional city. He was diagnosed with Crohn's disease three years ago and his condition caused him a lot of disruption and anxiety during his study. With symptoms often active, Nick is worried he won't be able to handle a full-time job. The pain and bleeding also prevent him from seeing his friends as much as he wants. Sometimes, he feels that his friends think he is weird.

Nick has occasionally seen a specialist over the past years. The medications sometimes work but sometimes don't, and he finds it difficult to relate his conditions to the specialist. He'd like to have more information about diet or other things to manage his health better. He tries to look up information on the internet, but the amount of information is overwhelming and much of it is confusing. He just can't figure out what the best care is for himself and he is very worried about his future.

Vignette 6: Cluster K – Li-ling

Li-ling is 50 and arrived in Australia with her parents when she was 14. The family settled in Melbourne. She had some tummy trouble in year 12, which got progressively worse over a few years until she went to a GP and was finally diagnosed with Crohn's disease. In 2020, Li-ling's 18-year-old daughter, Grace, was also diagnosed with Crohn's and was in and out of hospital with pain and vomiting. Because of COVID-19 and the Victorian lockdown, Li-ling usually had to leave Grace alone, and often crying, in hospital.

Li-ling sometimes goes to a GP when her symptoms get really bad, but she wishes they would ask her about more than just her bowel. Her joints are sore and sometimes swollen (Panadol helps a bit) and she is often very tired. She is anxious and feels kind of helpless about Grace's health because it is more severe than her own. She gets confused about the advice given to Grace because it is different to what she was told at the same age. She doesn't know where to get more information. Li-ling wants to know how other people manage and wonders about IBD support groups but wouldn't know how to find or approach one.

Vignette 7: Cluster L – Michael

Michael is 39 and a truck driver in a regional area. He was diagnosed with Crohn's disease nearly 10 years ago when his pain was so bad that his then girlfriend (now wife) dragged him along to see a doctor. He is much better now when he takes the medication his specialist in the city put him on. However, he can forget to take it when he is out on the road working long shifts.

He knows his wife wants to support him, but he isn't home often enough, and she's also always busy with their two young children when he is at home. Michael has recently noticed that he has an open sore that remains open for several weeks. However, he doesn't have a regular GP and his mates brush it off as just a wound. He has always been suspicious of the side effects of Crohn's medications. Now, he worries that something might have changed his health situation and he is confused and scared as hell.

Vignette 8: Cluster M – Mary

Mary is 65 and was diagnosed with Crohn's disease in her early 30s when she was home looking after 3 small children who are now grown and live in other states. She lives on the outskirts of a rural town – it takes 7 hours to drive to the main city and she doesn't drive. Mary's husband used to drive her to the IBD clinic in the city, but he died 5 years ago. She has occasionally caught a bus to the clinic, but it is a long journey, and she doesn't like staying overnight by herself. The pandemic restrictions make travel more difficult, so she hasn't been to the clinic for nearly two years now.

The GP in town is quite good and prescribes the medication she needs but Mary still finds it difficult and embarrassing to talk to him about her "toileting issues". She misses the nurses at the IBD clinic who really understand her, but she doesn't have a computer and wouldn't know how to do a telehealth appointment. She knows what she can and can't eat and does what she needs to do each day to manage her symptoms.

2. Ideas generation consultation – workshops and online activity

Online ideas generation workshops were held with people with IBD, carers, and health professionals. A total of 76 people took part: 38 people with IBD and carers (often also people with IBD) and 38 health professionals.

These consultation activities were conducted as described in Progress Report 1 using the 4 questions to guide discussions in workshops about ideas to improve information and resources for people with IBD. Additionally, the vignettes and the 4 questions were administered to health professionals and young people via a Qualtrics link. Participants were asked to answer the questions about 2 vignettes and were given an option to answer questions for more vignettes.

A list of the online workshops and Qualtrics activities conducted is displayed in Table 1.

Table 1. Ideas generation workshops conducted

Consultation activities	No. attended
Workshop 1 – Health professionals	5
Workshop 2 – Health professionals	4
Workshop 3 – Health professionals	2
Workshop 4 – People with IBD / Carers	7
Workshop 5 – People with IBD / Carers	7
Workshop 6 – People with IBD / Carers	7
Workshop 7 – People with IBD / Carers	6
Workshop 8 – Young people with IBD	7
Workshop 9 – Project advisory group	4*
Qualtrics activity 1 – Health professionals	25
Qualtrics activity 2 – Young people	2
Total	**76**

* 2 health professionals and 2 consumer representatives (people with IBD)

A summary of participants is displayed in Table 2.

Table 2. Number of participants taking part in ideas generation consultations

Participants	Number in Zoom workshops	Number in Qualtrics activity	Total
Health professionals	13	25	**38**
People with IBD and carers	29	-	**29**
Young people (15-30 years)	7	2	**9**
Total	**49**	**27**	**76**

The professions shown in Table 3 for the Qualtrics activity are for all the health professionals who consented to the Qualtrics activity. Of the 36 health professionals who consented and gave their profession and state in which they practice, 25 went on to answer questions about vignettes. Note that the numbers given in Table 3 for the Qualtrics activity are all the health professionals who consented – the professions of the 25 who answered questions could not be identified from the anonymous data.

Table 3. Professions of health professionals (n=25) across ideas generation consultations

Professions	Zoom workshops	Qualtrics activity*
Gastroenterologist	6	17
Paediatric gastroenterologist	2	-
Psychologist	1	1
IBD nurse	2	14
Dietitian	2	1
Pharmacist	-	1
Total	**13**	**36**

*The professions of all 36 health professionals who consented to the Qualtrics activity although only 25 answered questions about the vignettes

Table 4 shows the Australian States in which health professionals practice. Again, the numbers for the Qualtrics activity are for all 36 health professionals who consented and gave their profession and the state in which they practice.

Table 4. Australian States in which health professionals practice

State	Zoom workshops	Qualtrics activity*
Australian Capital Territory	-	2
New South Wales	3	12
Queensland	1	9
South Australia	2	5
Victoria	6	5
Western Australia	1	3
Total	**13**	**36**

*The states in which all 36 health professionals who consented to the Qualtrics activity although only 25 answered questions about the vignettes

3. Themes and ideas from data analysis

Analysis of the action ideas generated by the workshops and Qualtrics activity yielded 70 different ideas. These action ideas were thematically analysed, with 6 themes detected that range from ideas for person-centred actions through to ideas for actions at the policy level. The action ideas are displayed within the 6 themes. A list of the 70 actions ideas is attached as an appendix to this report.

3.1 Communicate in effective ways and understand the needs and perspectives of community members

Many ideas came up about improving communication between clinicians and people with IBD and carers as well as among clinicians of different disciplines treating people with IBD.

Improvements to communication included for clinicians to proactively ask patients about their perspectives and experiences of IBD, to engage families and carers in consultations, to improve communication techniques, and to ensure culturally sensitive communication with interpreters as needed.

- Communicate information to people with IBD from culturally diverse groups in culturally sensitive ways, in relevant languages, and with interpreters when needed
- Develop clear IBD management and self-management plans with people with IBD and carers
- Encourage clinicians to ask their patients with IBD about their perspectives and experiences of IBD
- Encourage clinicians to communicate with people with IBD about all aspects of IBD information, treatment, management, available services, support groups, topics of future concern (e.g., pregnancy)
- Encourage clinicians to consider asking medical students to leave (e.g., for older people) to reduce embarrassment
- Encourage clinicians to consider long consultations especially the initial consultation
- Encourage clinicians to engage families and carers in consultations for information about IBD, treatment and management while maintaining the discussion focus on the person with IBD
- Encourage clinicians to provide patients in remission with reassurance and information about IBD management - e.g., remain engaged with medical team
- Encourage people with IBD to proactively communicate with the clinicians in their multidisciplinary medical team to take ownership of their IBD, to advocate for themselves, to express how they feel and to ask questions
- Encourage proactive, sensitive and calm communication from clinicians to patients, including providing accessible information (e.g., graphics or images for young people), to improve rapport, reduce embarrassment and support discussions about sensitive information
- Improve communication among multidisciplinary IBD teams - i.e., among GPs, IBD services and specialists
- Increase access to flexible use of telehealth (by phone or computer) for multidisciplinary care, especially for regional/rural and for people who travel
- Organise demographic mapping of patients to providers (e.g., according to age, culture or language)
- Organise support from nurses, social workers, IBD medical teams, local nurse navigators to arrange appointments, IBD treatment and management, help understand online information, especially for people in regional/rural areas
- Train clinicians in Teachback, motivational interviewing, and best practice communication techniques, and provide supporting resources

3.2 Make access to services, information and technology easy

Access to services for people in regional and rural areas of Australia was frequently proposed in the ideas generation consultations. This often involved improving access to technology (e.g., computers, internet) and space (e.g., a private room) needed for telehealth appointments. Suggestions for improvement to access also included the support and services needed for people to seek multidisciplinary care early after diagnosis and for young people to get the support they need when transitioning from child to adult care.

- Advocate for libraries and community centres to provide IBD resources for people to connect to CCA or support groups, especially in regional/rural areas
- Arrange for libraries, community centres, GPs, and hospitals to provide computer and room for telehealth with multidisciplinary IBD practitioners for people with no access
- Improve access to technology (e.g., computer, internet) and train people with IBD to use technology and to access online services, especially older people and people in regional/rural areas
- Provide support to young people to establish treatment, multidisciplinary care and management of IBD early after diagnosis, and to put their health as a high priority
- Refer and encourage people with IBD to seek multidisciplinary care
- Support and empower young people transitioning from child to adult care - e.g., train/support independent communication with clinicians, get overlapping child and adult appointments, and provide appropriate resources

3.3 Support community connections, social networks, and mental health care

A strong argument throughout the data was that of connecting people with IBD with other people with IBD for social, emotional, and practical support. Mental health support was proposed for all people with IBD but especially for people who are isolated in some way, such as in regional and rural areas, and especially when needing to travel long distances for medical care. CCA was seen as being able to support connections to community, whether that be for socialising, sharing experiences of IBD and treatments, practical help for travelling or finding accommodation, or for more formal counselling and mental health support.

- Connect people with IBD to other people with IBD for reassurance and social/emotional support through structured programs and organisations
- Encourage people with IBD from the same family to support each other but to have separate support networks and consultations - e.g., consultations with young people without their parents or carers
- Encourage people with IBD to take their carers, family or other support people to their support groups
- Encourage people with IBD to use mental and emotional support techniques and tools - e.g., mindfulness, relaxation, exercise, meditation
- Increase access to and encourage people with IBD to seek mental health assessment and support, especially for people in regional/rural areas
- Organise counselling support for people with IBD including in regional/rural areas - e.g., for men, young people
- Organise for hospitalised children with IBD to be placed in wards with other children with IBD so they can talk about what they are going through
- Organise social and travel support for people with IBD from local and regional/rural areas
- Organise social support during hospital stays and provide IBD support resources and access to multidisciplinary care at discharge

- Promote IBD support groups, helplines and services (e.g., run by CCA, local groups) to the public (including multicultural groups, regional/rural) and to clinicians (e.g., GPs, IBD nurses, specialists)
- Support families and carers to care for themselves as well as the person with IBD including information about IBD treatment, management, mental health, and with the support of social workers in regional/rural areas

3.4 Develop, make accessible and distribute information and resources

This theme encompasses action ideas about CCA researching and developing information and resources and working to make these easily accessible largely through CCA communication channels, as well as distribution to clinicians and education institutions. The types of information and resources include reminder toolkits for self-management, an app to support access to tailored information and to connect to clinicians, information for people with different needs (e.g., in retirement, regional and rural), and an online directory of national IBD services and practitioners.

- Conduct research into IBD management techniques - e.g., dietary therapies, symptom management in retirement, keeping calm
- Develop a reminder toolkit to manage health and to support self-management activities
- Develop an app for people with IBD to get tailored information and connect to clinicians
- Develop and facilitate programs and support groups online, in-person and hybrid online/in-person
- Educate, support and provide resources for people with IBD to talk with family, friends and employers about IBD and the support they need
- Establish a position statement about the role of diet in IBD
- Increase access to targeted information and resources for people with different needs - e.g., adjustment to retirement, fertility and pregnancy, regional/rural
- Provide a helpline run by an IBD nurse for questions and advice about IBD, services and clinicians, especially for regional/rural areas
- Provide access to clear and easy to understand evidence-based IBD information, helplines, resources, services (including mental health and diet), financial assistance (e.g., free or bulk billed services), and other support
- Provide advice, support and an information pack to people who are newly diagnosed with IBD about where to find credible IBD information and resources
- Provide an online directory of national IBD services and clinicians (centralised and mobile) - e.g., for regional/rural and for people who travel
- Provide IBD resources to clinicians to give to people with IBD
- Provide resources to schools, universities and other institutions to support students with IBD

3.5 Raise public awareness of CCA and knowledge about IBD

There was a strong focus in the ideas generated for CCA to conduct activities to raise public awareness about IBD including with health professionals. Ideas included CCA conducting campaigns and other awareness raising activities as well as encouraging clinicians to raise awareness about CCA among their patients with IBD, and to provide clinicians with resources for themselves and their patients.

- Acknowledge and address how having IBD affects mental health
- Actively monitor media stories about IBD and contact media to get CCA information into news stories
- Build a strong online presence for CCA (e.g., improve website, SEO for Google traffic) for IBD support, resources, and connections to other people with IBD
- Educate employers about IBD - e.g., to support employees with IBD, to tackle discrimination
- Educate people with IBD, their family and carers about evidence-based IBD information, treatments, medications, and multidisciplinary management
- Educate the Australian general public and clinicians (e.g., GPs) about IBD including in regional/rural areas - e.g., distributing pamphlets through health clinics and hospitals, advertising, marketing and networking
- Encourage clinicians to direct people with IBD to CCA by the 2nd or 3rd consultation after diagnosis
- Encourage people to join CCA
- Organise events to raise awareness, provide information, and support people with IBD and their families - e.g., campaigns, camps for children, family and community education days and events, consumer conferences, IBD awareness month
- Promote CCA in clinics using posters and leaflets
- Raise awareness among clinicians about IBD and provide IBD information and resources (e.g., checklist for what a person with IBD needs, pre-consultation checklist for patients to self-report worries, problems and comfort with talking about health)
- Raise awareness and educate ethnic groups about IBD through culturally appropriate campaigns
- Raise awareness and encourage people with IBD and the general public to talk about IBD, gut health, and IBD stigma with family, friends and work colleagues to normalise these conversations - e.g., through conversations with influential people
- Raise awareness for parents and carers to contact CCA
- Reduce the stigma about seeing a psychologist
- Review other successful public health campaigns for ideas to promote and raise awareness about IBD

3.6 Advocate for policy at government level

As a consumer advocacy body, it was proposed that CCA could advocate for people with IBD at a federal level for inclusion of IBD in funding and healthcare schemes (e.g., NDIS), technology infrastructure (e.g., for internet services), and to improve access to timely multidisciplinary care (e.g., bulk billed services). Ideas for advocacy also included improvement to local health systems, services (including mobile services for regional and rural areas), facilities, and care and after-care pathways including proactive outreach and follow up services. Ideas were also raised about advocating to include education about IBD in medical and nursing student university curriculums, school curriculums (including supporting school students with IBD), and to involve young people in IBD service design.

- Advocate for funding (e.g., bulk billing, government) for people with IBD to access multidisciplinary care, especially in regional/rural areas
- Advocate for IBD to be included in funding / healthcare schemes - e.g., NDIS
- Advocate for internet infrastructure in regional/rural areas
- Advocate for local health systems, services, facilities (to attract clinicians), and mobile services in regional/rural areas
- Improve access to timely support and multidisciplinary IBD care especially in regional/rural areas
- Improve care and after-care pathways - e.g., GP software to flag IBD tests, easy referral pathway, support after diagnosis, proactive outreach and follow up, especially in regional/rural areas
- Include IBD in medical and nursing student education curriculums (e.g., diagnosis, treatment, management, consulting with carers/family, mental health)
- Include IBD in the school curriculum
- Involve young people in IBD service design

4. Next steps – Phase 2

4.1 Phase 2 ethics

The ethics for the activities of Ophelia Phase 2 has been submitted to the Swinburne ethics committee and has been approved. The approved activities include the ratings activities and workshops with key CCA stakeholders to rate and prioritise the actions that will be developed and tested in Phase 2 to prepare for implementation in Phase 3.

4.2 Phase 2 workshop to prioritise action ideas for development and testing

This workshop will be held on Tuesday, 15 June from 7 to 9pm. Prior to the workshop, key CCA staff and the project advisory group will rank the ideas according to a ranking instrument that has been provided by the Swinburne research team.

Appendix 1. CCA action ideas generated from ideas generation activities

1. Acknowledge and address how having IBD affects mental health
2. Actively monitor media stories about IBD and contact media to get CCA information into news stories
3. Advocate for funding (e.g., bulk billing, government) for people with IBD to access multidisciplinary care, especially in regional/rural areas
4. Advocate for IBD to be included in funding / healthcare schemes - e.g., NDIS
5. Advocate for internet infrastructure in regional/rural areas
6. Advocate for libraries and community centres to provide IBD resources for people to connect to CCA or support groups, especially in regional/rural areas
7. Advocate for local health systems, services, facilities (to attract clinicians), and mobile services in regional/rural areas
8. Arrange for libraries, community centres, GPs, and hospitals to provide computer and room for telehealth with multidisciplinary IBD practitioners for people with no access
9. Build a strong online presence for CCA (e.g., improve website, SEO for Google traffic) for IBD support, resources, and connections to other people with IBD
10. Communicate information to people with IBD from culturally diverse groups in culturally sensitive ways, in relevant languages, and with interpreters when needed
11. Conduct research into IBD management techniques - e.g., dietary therapies, symptom management in retirement, keeping calm
12. Connect people with IBD to other people with IBD for reassurance and social/emotional support through structured programs and organisations
13. Develop a reminder toolkit to manage health and to support self-management activities
14. Develop an app for people with IBD to get tailored information and connect to clinicians
15. Develop and facilitate programs and support groups online, in-person and hybrid online/in-person
16. Develop clear IBD management and self-management plans with people with IBD and carers
17. Educate employers about IBD - e.g., to support employees with IBD, to tackle discrimination
18. Educate people with IBD, their family and carers about evidence-based IBD information, treatments, medications, and multidisciplinary management
19. Educate the Australian general public and clinicians (e.g., GPs) about IBD including in regional/rural areas - e.g., distributing pamphlets through health clinics and hospitals, advertising, marketing and networking
20. Educate, support and provide resources for people with IBD to talk with family, friends and employers about IBD and the support they need
21. Encourage clinicians to ask their patients with IBD about their perspectives and experiences of IBD
22. Encourage clinicians to communicate with people with IBD about all aspects of IBD information, treatment, management, available services, support groups, topics of future concern (e.g., pregnancy)
23. Encourage clinicians to consider asking medical students to leave (e.g., for older people) to reduce embarrassment
24. Encourage clinicians to consider long consultations especially the initial consultation
25. Encourage clinicians to direct people with IBD to CCA by the 2nd or 3rd consultation after diagnosis

26. Encourage clinicians to engage families and carers in consultations for information about IBD, treatment and management while maintaining the discussion focus on the person with IBD
27. Encourage clinicians to provide patients in remission with reassurance and information about IBD management - e.g., remain engaged with medical team
28. Encourage people to join CCA
29. Encourage people with IBD from the same family to support each other but to have separate support networks and consultations - e.g., consultations with young people without their parents or carers
30. Encourage people with IBD to proactively communicate with the clinicians in their multidisciplinary medical team to take ownership of their IBD, to advocate for themselves, to express how they feel and to ask questions
31. Encourage people with IBD to take their carers, family or other support people to their support groups
32. Encourage people with IBD to use mental and emotional support techniques and tools - e.g., mindfulness, relaxation, exercise, meditation
33. Encourage proactive, sensitive and calm communication from clinicians to patients, including providing accessible information (e.g., graphics or images for young people), to improve rapport, reduce embarrassment and support discussions about sensitive information
34. Establish a position statement about the role of diet in IBD
35. Improve access to technology (e.g., computer, internet) and train people with IBD to use technology and to access online services, especially older people and people in regional/rural areas
36. Improve access to timely support and multidisciplinary IBD care especially in regional/rural areas
37. Improve care and after-care pathways - e.g., GP software to flag IBD tests, easy referral pathway, support after diagnosis, proactive outreach and follow up, especially in regional/rural areas
38. Improve communication among multidisciplinary IBD teams - i.e., among GPs, IBD services and specialists
39. Include IBD in medical and nursing student education curriculums (e.g., diagnosis, treatment, management, consulting with carers/family, mental health)
40. Include IBD in the school curriculum
41. Increase access to and encourage people with IBD to seek mental health assessment and support, especially for people in regional/rural areas
42. Increase access to flexible use of telehealth (by phone or computer) for multidisciplinary care, especially for regional/rural and for people who travel
43. Increase access to targeted information and resources for people with different needs - e.g., adjustment to retirement, fertility and pregnancy, regional/rural
44. Involve young people in IBD service design
45. Organise counselling support for people with IBD including in regional/rural areas - e.g., for men, young people
46. Organise demographic mapping of patients to providers (e.g., according to age, culture or language)
47. Organise events to raise awareness, provide information, and support people with IBD and their families - e.g., campaigns, camps for children, family and community education days and events, consumer conferences, IBD awareness month

48. Organise for hospitalised children with IBD to be placed in wards with other children with IBD so they can talk about what they are going through
49. Organise social and travel support for people with IBD from local and regional/rural areas
50. Organise social support during hospital stays and provide IBD support resources and access to multidisciplinary care at discharge
51. Organise support from nurses, social workers, IBD medical teams, local nurse navigators to arrange appointments, IBD treatment and management, help understand online information, especially for people in regional/rural areas
52. Promote CCA in clinics using posters and leaflets
53. Promote IBD support groups, helplines and services (e.g., run by CCA, local groups) to the public (including multicultural groups, regional/rural) and to clinicians (e.g., GPs, IBD nurses, specialists)
54. Provide a helpline run by an IBD nurse for questions and advice about IBD, services and clinicians, especially for regional/rural areas
55. Provide access to clear and easy to understand evidence-based IBD information, helplines, resources, services (including mental health and diet), financial assistance (e.g., free or bulk billed services), and other support
56. Provide advice, support and an information pack to people who are newly diagnosed with IBD about where to find credible IBD information and resources
57. Provide an online directory of national IBD services and practitioners (centralised and mobile) - e.g., for regional/rural and for people who travel
58. Provide IBD resources to clinicians to give to people with IBD
59. Provide resources to schools, universities and other institutions to support students with IBD
60. Provide support to young people to establish treatment, multidisciplinary care and management of IBD early after diagnosis, and to put their health as a high priority
61. Raise awareness among clinicians about IBD and provide IBD information and resources (e.g., checklist for what a person with IBD needs, pre-consultation checklist for patients to self-report worries, problems and comfort with talking about health)
62. Raise awareness and educate ethnic groups about IBD through culturally appropriate campaigns
63. Raise awareness and encourage people with IBD and the general public to talk about IBD, gut health, and IBD stigma with family, friends and work colleagues to normalise these conversations - e.g., through conversations with influential people
64. Raise awareness for parents and carers to contact CCA
65. Reduce the stigma about seeing a psychologist
66. Refer and encourage people with IBD to seek multidisciplinary care
67. Review other successful public health campaigns for ideas to promote and raise awareness about IBD
68. Support and empower young people transitioning from child to adult care - e.g., train/support independent communication with clinicians, get overlapping child and adult appointments, and provide appropriate resources
69. Support families and carers to care for themselves as well as the person with IBD including information about IBD treatment, management, mental health, and with the support of social workers in regional/rural areas
70. Train clinicians in Teachback, motivational interviewing, and best practice communication techniques, and provide supporting resources

Centre for Global Health and Equity

CCA Ophelia Project
Progress report 3

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Friday, 20 January 2023

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Centre for Global Health and Equity
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CCA Ophelia Project – Progress Report 3

Introduction

This is Progress Report 3 for the Crohn's & Colitis Australia (CCA) project to apply the Ophelia (Optimising Health Literacy and Access) process to facilitate improvements to CCA resources for people with inflammatory bowel disease (IBD). This report describes the activities and outcomes of the evaluation of the new resources on the Crohn's & Colitis Australia (CCA) website. The new website resources were informed by the outcomes of extensive in-depth consultation (2020-2021) across Australia with people living with IBD, their health professionals, and carers of people with IBD. The consultation aimed to co-design actions for ways in which CCA could improve health information and services to support people living with IBD, and their carers, to manage their health.

Ophelia community consultation activities resulted in 70 action ideas (collated into 6 themes):

1. Communicate in effective ways and understand the needs and perspectives of community members (15 ideas)
2. Make access to services, information and technology easy (6 ideas)
3. Support community connections, social networks, and mental health care (11 ideas)
4. Develop, make accessible, and distribute information and resources (13 ideas)
5. Raise public awareness of CCA and knowledge about IBD (16 ideas)
6. Advocate for policy at government level (9 ideas)

CCA undertook a comprehensive and in-depth process to rate and prioritise the actions into those that CCA was already doing and will continue to do, those that could be implemented in the short term, those can could be considered for implementation in other projects that CCA is conducting, and those that could be implemented in the future. A detailed program logic, developed by CCA to align with organisational strategies, guided the implementation of the actions, primarily through improving and adding new resources to the updated CCA website.

1. The evaluation of the CCA website resources

The evaluation survey, including the consent process, was conducted by the Swinburne research team online using Qualtrics. People were invited to take part in the survey via CCA's social media outlets and through emails to respondents of the 2020 survey who provided consent to be contacted again about this research. The survey link was posted on the CCA website.

The purpose of the survey was to collect data from website users about their experiences with the resources on the website. Also collected were indicators of health literacy, eHealth literacy, and self-management outcomes, as well as demographic and some health information. The scales from the three questionnaires used in the survey are outlined in Table 1. HLQ Scale 4. 'Social support for health' was included in the first survey for this project (2020) but was not included in this evaluation survey because it is a component of health literacy that is not expected to change in the short time between these surveys.

Table 1. Questionnaires used in the evaluation survey

Questionnaires and scales
HLQ (Health Literacy Questionnaire) scales[1]
1. Feeling understood and supported by healthcare providers
2. Having sufficient information to manage my health
3. Actively managing my health
(4. Social support for health – not included)
5. Appraisal of health information
6. Ability to actively engage with healthcare providers
7. Navigating the healthcare system
8. Ability to find good health information
9. Understand health information well enough to know what to do
eHLQ (eHealth Literacy Questionnaire) scale[1]
5. Motivated to engage with digital services
heiQ (Health Education Impact Questionnaire) scales[2]
1. Health-directed activities
6. Skill and technique acquisition
Manitoba Index
Active Disease
Inactive Disease
Number of people attempting the survey[3] = 230
Complete and useable responses[4] = 148

1. Health literacy measurement instruments
2. Self-management outcomes instrument
3. Surveys from all respondents, including incomplete surveys
4. Surveys with complete data used in this analysis

The online survey was conducted from 2 September 2022 to 15 November 2022. A total of 230 people responded to the survey but not all people answered all questions. Although all survey responses were retained for the analysis of demographic and health information, incomplete responses were excluded for the analysis of the other data. Of the 230 surveys, 148 were retained for analysis of health literacy, eHealth literacy, and self-management data.

2. Demographic and health information

Table 2 shows that 70.3% (N = 145) of respondents were female, had an average age of 53 years (SD = 15.8, N = 145), with only 2.8% who were aged 15 – 25 years. Most respondents were born in Australia (89.5%, N = 143), with almost all speaking English at home (99.3%, N = 143). When compared with the population percentage of Aboriginal and Torres Strait Islander peoples in the 2021 Australian Bureau of Statistics census[1] (3.8%), there was a relatively high percentage of Aboriginal and Torres Strait Islander people who responded to this survey (2.8%, N = 143), although this percentage represents only 4 people.

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[1] Australian Bureau of Statistics. (June 2021). Estimates of Aboriginal and Torres Strait Islander Australians. Retrieved from https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-aboriginal-and-torres-strait-islander-australians/latest-release.

Most respondents lived in major cities (69%, N = 142) compared to 1% living in remote areas. On average, the respondents lived with another person (M = 2.4, SD = 1.6, N = 143) with 18% who lived alone. Half of the respondents had a university education (53%, N = 143). Many worked full-time (33%, N = 143) or part-time (26%), and a fifth were retired (22%). Many respondents worked in management and administration (20%, N = 79), education (19%), and health and allied services (18).

Table 2. Demographic information

Characteristics[1]	**n (%)**
Age (N = 145)	
Mean: Year (SD) Range: 21 – 79	52.66 (15.76)
15 – 25	4 (2.76)
26 – 40	34 (23.4)
41 – 55	38 (26.2)
56 – 70	46 (31.7)
71 or above	23 (15.9)
Gender (N = 145)	
Female	102 (70.3)
Male	41 (28.3)
Non-binary	2 (1.4)
Country of birth (N = 143)	
Australian born	128 (89.5)
Spoke English at home	142 (99.3)
Aboriginal and Torres Strait Islander	4 (2.8)
Number of household members	
Mean (SD) Range: 1 – 6	2.4 (1.16)
Lived Alone	25 (17.5)
Residence	
Major city	98 (69.0)
Inner regional	30 (21.1)
Outer regional	12 (5.5)
Remote or very remote	2 (1.4)
Education	
Primary school	1 (0.7)
High school	24 (16.8)
Trade certificate, apprenticeship, diploma or college/TAFE certificate	42 (29.4)
University undergraduate degree	45 (31.5)
University postgraduate degree (e.g., Master, PhD)	31 (21.7)
Employment	
Full-time	47 (32.9)
Part-time	37 (25.9)
Not working	9 (6.3)
Home duties	5 (3.5)
Student	2 (1.4)
Retired	31 (21.7)

Carer	5 (3.5)
Sickness and disability	6 (4.2)
Volunteer	1 (0.7)
Occupation sector	
Health and allied services	15 (17.9)
Education	16 (19.0)
Public sector	4 (5.1)
Finance and business	9 (10.7)
Management and administration	16 (20.3)
IT	2 (2.5)
Engineering and construction	2 (2.5)
Manufacturing and distribution	1 (1.2)
Security	1 (1.2)
Media and creative arts	2 (2.5)
Hospitality	3 (3.6)
Sales and retail	4 (5.1)

1. Not all of the 230 respondents answered every question. Survey respondents per question ranged from 79 to 145.

Health information about respondents is displayed in Table 3. Respondents were mainly people living with IBD (87%, 211 responses from 193 respondents). About half of the respondents (51%, N = 164) were diagnosed with IBD more than 10 years ago, and 48% were diagnosed between 2013 and 2022, of whom 15 were diagnosed in the past 12 months. About one-third (32%) responded that they have lived with IBD for the past 1 to 4 years. Of the 490 responses from 146 respondents (can be more than one response per person) to the question about long-standing illness or disability, people mostly reported Crohn's disease (18%), ulcerative colitis (11%), and other gastrointestinal (GI) conditions (3%). Furthermore, 17% out of 82 responses were for mental health conditions: anxiety (10%) and depression (6%). Of the 230 respondents who took part in the survey, 100 gave consent to be contacted again about this research.

The Manitoba Index (Clara et al., 2009) used in this survey used a 3-month timeframe instead of the traditional 6-month timeframe. The Manitoba Index is a single item measure that states “In the past 3 months my disease has been…” with six-level scale options, ranging from (a) my disease has been constantly active, to (f) I was well in the past 3 months, what I consider a remission or absence of symptoms. Answers for statements from (a) to (d) are grouped to indicate people who are experiencing active disease. Answers for statements (e) and (f) are grouped to indicate people who are experiencing inactive disease. Table 3 shows the responses from the Manitoba Index. Most respondents to this survey reported they experienced active disease (70%) over the past three months.

Table 3. Health information

Characteristics[1]	**n (%)**
I am… (N = 211)	
Living with IBD	184 (87.2)
Carer	10 (4.7)
Researcher	1 (0.5)
Health professional	9 (4.3)

Other	7 (3.3)
Number of years living with IBD	
Mean (SD) Range: 0 – 56	13.48 (12.71)
Less than 1 year	1 (0.6)
1 – 4 years	53 (32.3)
5 – 9 years	26 (15.9)
10 or more years	84 (51.2)
Year diagnosed with IBD	
1962 – 1972	1 (0.6)
1973 – 1982	6 (3.66)
1983 – 1992	15 (9.1)
1993 – 2002	29 (17.7)
2003 – 2012	33 (20.1)
2013 – 2022	80 (48.8)
Manitoba Index (past 3 months symptoms)	
(a) Constantly active, (every day)	33 (18.2)
(b) Often active, (most days)	47 (26.0)
(c) Sometimes active, (1-2 days a week)	25 (13.8)
(d) Occasionally active, (1-2 days a month)	22 (12.2)
(e) Rarely active, (few days over last 3 months)	21 (11.6)
(f) Symptoms in Remission or Absence	33 (18.23)
Long-standing illness or disability	
Crohn’s disease	86 (17.6)
Ulcerative colitis	53 (10.8)
Indeterminate colitis	6 (1.2)
Other GI conditions	9 (1.8)
Mental health	82 (16.7)
Anxiety	49 (10.0)
Depression	31 (6.3)
Arthritis or problems with your joints	54 (11.0)
Back pain	37 (7.6)
Lung problems or breathing problems	12 (2.4)
Kidney problems	5 (1.0)
Heart problems	13 (2.7)
Diabetes	9 (1.8)
Cancer	4 (0.8)
Other	40 (8.2)
Total number of long-standing illness per person	
One	43 (18.7)
Two	32 (13.9)
Three	24 (10.4)
Four	18 (7.8)
Five	13 (5.7)
Six or more	14 (6.1)

1. Not all of the 230 respondents answered every question. Survey respondents per question ranged from 146 to 211. Some questions allowed for more than one response.

3. Website feedback and resources

Fifty percent of people reported visiting the CCA website twice, ranging between one and two times, with four people each reporting they had visited the website four times. The website feedback questions (Table 4) were scored on a 4-point response option scale (1 Strongly disagree / 2 Disagree / 3 Agree / 4 Strongly agree). Respondents reported mostly positive interactions and experiences with the website, including that, on average, they trust the information and feel it was worth their time and effort to look at the information on the website. Respondents agreed that they intend to tell others that the website is useful, that the information will help them to manage their health, and that the website is well organised. Respondents also reported that difficult topics about IBD are handled well, the content is relevant to them, and that different perspectives are well represented.

Table 4. Website feedback

	N	Strongly Disagree %	Disagree %	Agree %	Strongly Agree %
I intend to tell other people that this website is useful	166	2.4	1.2	58.4	27.1
The CCA website contains information that will help me to manage my health	166	1.8	6.0	72.9	19.3
I trust the information and advice on this website	166	0.6	2.4	56.6	40.4
The information and resources on this website are well organised	165	0.6	7.3	67.3	24.8
I feel it was worth my time and effort to spend time looking at the information on this website	164	1.2	6.1	65.2	27.4
Difficult topics about IBD are handled well in the resources on this website	161	0.6	7.5	65.2	26.7
The website content is relevant to my situation	162	3.7	8.6	60.5	27.2
The perspectives of people with IBD are represented well on this website	162	1.2	8.6	63.0	27.2

The survey included three free text (qualitative) questions for respondents to write about why they accessed the website (N = 142), which resources they accessed (N = 109), and to give feedback about the website (N = 41). Data analysis revealed that these qualitative responses to two questions (why people accessed the website and which resources they accessed) often overlapped into responses about which website resources were accessed. For this reason, responses to these questions were combined and coded according to resources on the CCA website, resulting in 251 responses coded into 31 resource categories. Some responses included items of information that were coded to more than one resource category, resulting in 352 coded items of information. For example, the response "I am interested in new research and living well with Crohn's" was coded into three resource categories: "News (research and recipes)", "General information / About IBD", and "Living with IBD".

The main reasons people accessed the website was to view General information / About IBD (100 items of information) and News (research and recipes) (31 items). Of the people who completed the qualitative questions, 9 were diagnosed in the 12 months prior to them completing the survey. Their reasons for accessing the website were for General information / About IBD (6 items); Information following diagnosis (1 item); News (research and recipes) (1 item); eNews and magazines (2 items); IBD and Covid-19 information and vaccinations (1 item); Information forums (2 items); Medication and treatment (2 items); Support groups and services (1 item); Psychological health and IBD (1 item); Ulcerative colitis (UC) patient guide (1 item); and To do the survey (1 item).

Qualitative feedback about the website included 41 responses from 41 people. Much of the feedback was positive, with people reporting that they found it very helpful, useful, and that it provided comfort around getting more information from healthcare providers. Some people also commented that they would like more information about living with IBD, including broad types of information about low fibre diet, ileostomy, life insurance, a digital version of the Can't Wait Card for their phone, and a hardcopy of the IBD toolkit.

Three people reported issues with the website. One person found the website "difficult to access". A second person (diagnosed more than 12 months ago) found the information "not easy to find" and felt like the information tended to "gloss over many systemic symptoms". This person also found the website had an "extreme focus on young people recently diagnosed". A third person (diagnosed in the past 12 months) commented that "the website seems to concentrate on young people and ageing people have other additional issues". Furthermore, this person would like more information to assist people living in regional Australia.

Table 5. Number of items of information from qualitative responses coded to categories of CCA website resources

	N (%)
About IBD	
General information / About IBD	100 (29.2)
CCA membership	9 (2.6)
Information following diagnosis	5 (1.5)
Information forums	8 (2.3)
Ulcerative colitis (UC) patient guide	1 (0.3)
IBD Toolkit	2 (0.6)
Information for carers	2 (0.6)
IBD service locator	2 (0.6)
CCA projects	2 (0.6)
News (research and recipes)	31 (9.1)
eNews / Magazine	14 (4.1)
Support	

Support groups / services	17 (5.0)
NurseLine or Helpline	5 (1.5)
Other people’s experiences	9 (2.6)
How to help	1 (0.3)
Medical	
Complications of IBD	1 (0.3)
Medication and treatment	32 (0.4)
COVID information and vaccinations	12 (5.5)
Lifestyle	
Exercise	1 (0.3)
Nutrition	19 (5.6)
IBD and travel	1 (0.3)
Fertility, pregnancy and IBD	2 (0.6)
Psychological health and IBD	8 (2.3)
Fatigue	3 (0.9)
Workplace and financials	3 (0.9)
Can’t wait card	2 (0.6)
Living with IBD	5 (1.5)
CCA events	2 (0.6)
Additional reasons	
To see the new website	11 (3.2)
To do the survey	25 (7.3)
Other	5 (1.5)

4. Health literacy, eHealth literacy, and self-management information

This section of the survey included questions about health literacy (HLQ), digital health literacy (eHLQ), and self-management (heiQ). There were 148 complete surveys that could be used for this analysis.

The HLQ has two parts: scales in Part 1 are scored on a 4-point response option scale (1 Strongly disagree / 2 Disagree / 3 Strongly agree / 4 Agree) and scales in Part 2 are scored on a 5-point response option scale (1 Cannot do or always difficult / 2 Usually difficult / 3 Sometimes difficult / 4 Usually easy / 5 Always easy). The eHLQ and heiQ both use the 4-point agreement response options. Scores above 2.5 for the 1 to 4 scoring range indicate that respondents tend to agree with the items in that scale. Scores above 3.5 in the 1 to 5 scoring range indicate that respondents tend to find the tasks in the items easy or very easy to do. Means and standard deviation (SD) for each of the scales are shown in Table 6.

In Part 1 of the HLQ, the highest mean scale score was for Scale 1 ‘Feeling understood and supported by healthcare providers’ (M = 3.39, SD = 0.24) and the lowest was for Scale 2 ‘Having sufficient information to manage my health’ (M = 2.91, SD = 0.32). This indicates that although the respondents to this survey tend to agree that they have an established relationship with at least one healthcare provider they trust, they may not feel as confident about having all the information they need to manage and make decisions about their health. In Part 2, the highest mean scale score was for Scale 9 ‘Understand health information well enough to know what to do’ (M = 4.00, SD = 0.54) indicating that respondents are generally able to understand information about their health and complete health forms when required. The lowest mean scale score was for Scale 7 ‘Navigating the healthcare system’ (M=3.46, SD= 0.56), which is slightly below 3.5, indicating that respondents have some difficulty in being able to find the services and supports they need for their health.

On average, respondents tend to disagree that health is important and they may not take full responsibility for their health (Scale 3 ‘Actively managing my health’: M = 2.95, SD = 0.43), and some people may have some trouble assessing health information to identify good information from reliable sources and resolve issues to do with conflicting information (Scale 5 ‘Appraisal of health information’: M = 2.96, SD = 0.37). Similarly, scores for Scales 6 ‘Ability to actively engage with healthcare providers’ (M = 3.72, SD = 0.54) and 8 ‘Ability to find good health information’ (M = 3.75, SD = 0.53) indicate that some respondents have challenges with engaging with and seeking information and advice from their healthcare providers, and struggle a little to find a diverse range of up-to-date information about their health.

The score for eHLQ Scale 5 ‘Motivated to engage with digital services’ (M = 2.87, SD =0.51) indicates that respondents generally disagree that engaging with digital health services will help them to manage their health. The two heiQ scale scores suggest that respondents could have some challenges in engaging in healthy behaviours, including exercise, (heiQ Scale 1 ‘Health-directed activities’: M = 2.92, SD = 0.81) and in developing ways to help them to cope with symptoms and health problems (heiQ Scale 6 ‘Skill and technique acquisition’: M = 2.83, SD = 0.59).

Table 6. HLQ, eHLQ and heiQ scale scores (N = 148)

	Mean (SD)
	Score range: 1 (lowest) – 4 (highest)
HLQ	
1. Feeling understood and supported by healthcare providers	3.39 (0.24)
2. Having sufficient information to manage my health	2.91 (0.32)
3. Actively managing my health	2.95 (0.43)
5. Appraisal of health information	2.96 (0.37)
	Score range: 1 (lowest) – 5 (highest)
6. Ability to actively engage with healthcare providers	3.72 (0.54)
7. Navigating the healthcare system	3.46 (0.56)
8. Ability to find good health information	3.75 (0.53)
9. Understand health information well enough to know what to do	4.00 (0.54)
	Score range: 1 (lowest) – 4 (highest)
eHLQ	
5. Motivated to engage with digital services	2.87 (0.51)
heiQ	
Scale 1. Health-directed activities	2.92 (0.81)
Scale 6. Skill and technique acquisition	2.83 (0.59)

5. Conclusion

Overall, the cohort of people who responded to this survey generally feel understood and supported by healthcare professionals and they understand health information well enough to know what to do. Areas in which some respondents may have challenges include having sufficient health information and being able to evaluate it, as well as being able to navigate the healthcare system to find the services they need. These data indicate that the resources provided by CCA on the website may assist people with IBD and their carers because the information is from reliable and trusted sources, it is all in one place, and it can help direct people to appropriate IBD and other relevant services. New resources are being added to the CCA website and the final evaluation survey (third survey for the whole project) will take place in mid-2023.

Reference

Clara I, Lix LM, Walker JR, Graff LA, Miller N, Rogala L, Rawsthorne P, Bernstein CN. The Manitoba IBD Index: evidence for a new and simple indicator of IBD activity. Am J Gastroenterol. 2009 Jul;104(7):1754-63. doi: 10.1038/ajg.2009.197. Epub 2009 May 19. PMID: 19455122.

Appendix 4: Google analytics new CCA website evaluation

Google analytics new CCA website evaluation

Webpage title	Date published	Total views from date published to 30/08/2023	Unique views from date published to 30/08/2023	Average engagement time (secs) from date published to 30/08/2023
About Crohn's and Colitis	9/03/2022	38,258	30,052	20.97
Crohn's Disease	9/03/2022	18,567	14,602	24.02
About Crohn's Disease	9/03/2022	8,986	7,190	76.07
Crohn's Disease Symptoms	9/03/2022	20,843	18,417	37.33
Crohn's Disease Diagnosis	9/03/2022	8,618	7,514	51.27
Crohn's Disease Treatment	9/03/2022	11,217	9,278	106.00
Ulcerative Colitis	9/03/2022	16,344	13,081	25.68
About Ulcerative Colitis	9/03/2022	4,715	3,769	76.21
Ulcerative Colitis Symptoms	9/03/2022	9,618	8,619	31.77
Ulcerative Colitis Diagnosis	9/03/2022	2,953	2,585	54.89
Ulcerative Colitis Treatment	9/03/2022	6,662	5,119	106.86
Other Types of IBD	9/03/2022	609	553	27.21
IBD Unclassified	9/03/2022	1212	1071	66.87
Microscopic Colitis	9/03/2022	1,546	1,127	167.80
Young people with IBD (content page removed to allow for new structure below)	9/03/2022	1,117	855	52.33
Students with IBD (content page removed to allow for new structure below)	9/03/2022	501	367	89.79
Moving from Paediatric to Adult Care (content page removed to allow for new structure below)	9/03/2022	110	75	42.76
Young People with Crohn's and Colitis	17/11/2022	2,145	1,619	21.40
Crohn's and Colitis Kids	17/11/2022	648	548	103.09
Crohn's and Colitis Teens	17/11/2022	854	658	119.65
Crohn's and Colitis Parents	17/11/2022	281	237	54.82
Moving from Paediatric to Adult Care	17/11/2022	103	94	39.10
Students with IBD	17/11/2022	646	435	123.43
Differentiating between IBD and IBS	19/01/2023	813	664	65.92
Living with Crohn's and Colitis	9/03/2022	3,285	2,510	16.97
Lifestyle	9/03/2022	3,055	2,143	23.70
Exercise	9/03/2022	1,940	1,600	88.10
Nutrition	9/03/2022	17,895	13,118	124.43
Optimising Bone Health in IBD	27/06/2023	139	93	146.88
Anaemia in IBD	27/06/2023	136	102	133.98
Exclusive Enteral Nutrition for Crohn's disease	27/06/2023	211	161	64.69
Managing a High Output Stoma in IBD	27/06/2023	94	61	74.03
Frequently Asked Dietary Questions in IBD	27/06/2023	248	169	112.07
Eating Well When Feeling Unwell with IBD	6/09/2023	n/a	n/a	n/a
Travel and IBD	9/03/2022	1,409	1,114	79.00
Fertility, Pregnancy and IBD	9/03/2022	1,471	1,177	105.94
Sexuality and IBD	9/03/2022	782	711	72.82
Psychological Health and IBD	9/03/2022	2,510	1,885	73.71
Fatigue	9/03/2022	1,504	1,181	134.64
My Partner in Care	9/03/2022	643	473	62.01
Content included in "Remission" webpage	n.a	n.a	n.a	n.a
Medical	9/03/2022	1,701	1,245	21.44
Complications of IBD	9/03/2022	1,337	1,032	116.11
Other Conditions Connected to IBD	9/03/2022	603	443	162.53
Medication for IBD	9/03/2022	5,500	3,788	53.95
Adalimumab for IBD	9/03/2022	607	472	112.84
Aminosalicylates (5-ASAs) for IBD	9/03/2022	527	459	101.28
Complementary and Alternative Medicine in IBD	9/03/2022	942	815	83.07
Corticosteroids for IBD	9/03/2022	477	366	114.28
Golimumab for IBD	9/03/2022	263	226	69.81
Infliximab for IBD	9/03/2022	1,059	811	103.68
Methotrexate for IBD	9/03/2022	369	312	105.34
Thiopurines (Mercaptopurine and Azathioprine) fo	9/03/2022	880	637	98.00
Tofacitinib for IBD	9/03/2022	524	417	80.76
Ustekinumab for IBD	9/03/2022	706	567	94.60
Vedolizumab for IBD	9/03/2022	1,329	1,044	84.29
Surgery	9/03/2022	954	760	92.41
Life with a stoma	9/03/2022	135	103	93.41
Medical Terms	9/03/2022	136	119	52.65
Remission	9/03/2022	467	400	90.39
Covid-19 and IBD	9/03/2022	1,677	1,418	54.59
Vaccinations and IBD	9/03/2022	368	315	70.27
Workplace and Financials (topics now seperated as below)	9/03/2022	1,339	991	32.08
Workplace	26/06/2023	111	77	22.17
Working with IBD – A Guide for Employers	9/03/2022	3,018	2,357	118.61
Working with IBD – A Guide for Employees	9/03/2022	1,861	1,506	121.83
Financial	26/06/2023	1,083	803	99.23
Rural and Remote Support	20/07/2023	170	99	46.14
Supporting Someone with IBD	17/11/2022	639	514	53.89
Communicating About my IBD	17/11/2022	584	470	70.47
Useful links	9/03/2022	839	693	41.30
Support	9/03/2022	1,947	1,437	21.31
IBD Service Locator	9/03/2022	1,680	1,214	40.74
Connect with a peer	9/03/2022	977	455	52.08
Support Groups	9/03/2022	5,114	3,635	43.70
Information Forums	9/03/2022	2,314	1,509	27.64
CCA QR Poster for Clinics	12/08/2022	247	121	48.13
Resources in Other Languages	2/05/2023	354	77	41.27
Arabic	2/05/2023	Unable to retrieve data		
About Crohn's Disease	2/05/2023	Unable to retrieve data		
Crohn's Disease Symptoms	2/05/2023	Unable to retrieve data		
Crohn's Disease Diagnosis	2/05/2023	Unable to retrieve data		
Crohn's Disease Treatment	2/05/2023	Unable to retrieve data		
About Ulcerative Colitis	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Symptoms	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Diagnosis	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Treatment	2/05/2023	Unable to retrieve data		
Farsi	2/05/2023	Unable to retrieve data		
About Crohn's Disease	2/05/2023	Unable to retrieve data		
Crohn's Disease Symptoms	2/05/2023	Unable to retrieve data		
Crohn's Disease Diagnosis	2/05/2023	Unable to retrieve data		
Crohn's Disease Treatment	2/05/2023	Unable to retrieve data		
About Ulcerative Colitis	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Symptoms	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Diagnosis	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Treatment	2/05/2023	Unable to retrieve data		
Punjabi	2/05/2023	Unable to retrieve data		
About Crohn's Disease	2/05/2023	Unable to retrieve data		
Crohn's Disease Symptoms	2/05/2023	Unable to retrieve data		
Crohn's Disease Diagnosis	2/05/2023	Unable to retrieve data		
Crohn's Disease Treatment	2/05/2023	Unable to retrieve data		
About Ulcerative Colitis	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Symptoms	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Diagnosis	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Treatment	2/05/2023	Unable to retrieve data		
Simplified Chinese	2/05/2023	Unable to retrieve data		
About Crohn's Disease	2/05/2023	Unable to retrieve data		
Crohn's Disease Symptoms	2/05/2023	Unable to retrieve data		
Crohn's Disease Diagnosis	2/05/2023	Unable to retrieve data		
Crohn's Disease Treatment	2/05/2023	Unable to retrieve data		
About Ulcerative Colitis	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Symptoms	2/05/2023	Unable to retrieve data		
Ulcerative Colitis Diagnosis	2/05/2023	Unable to retrieve data		

Ulcerative Colitis Treatment	2/05/2023	Unable to retrieve data
Vietnamese	2/05/2023	Unable to retrieve data
About Crohn's Disease	2/05/2023	Unable to retrieve data
Crohn's Disease Symptoms	2/05/2023	Unable to retrieve data
Crohn's Disease Diagnosis	2/05/2023	Unable to retrieve data
Crohn's Disease Treatment	2/05/2023	Unable to retrieve data
About Ulcerative Colitis	2/05/2023	Unable to retrieve data
Ulcerative Colitis Symptoms	2/05/2023	Unable to retrieve data
Ulcerative Colitis Diagnosis	2/05/2023	Unable to retrieve data
Ulcerative Colitis Treatment	2/05/2023	Unable to retrieve data

Appendix 5: Survey 1 and Survey 3 score comparisons

Survey 1 and Survey 3 score comparisons

A comparison of the HLQ and eHLQ scores between Survey 1 and Survey 3 was also undertaken. Given Survey 1 did not have any of the 8 statements of the evaluation questions as in Surveys 2 and 3, only HLQ and eHLQ scores could be compared.

Participant characteristics – Surveys 1 and 3

A total of 41 participants were found to have completed both Survey 1 and Survey 3 (Table 11). The demographic characteristics of these 41 participants are similar to the full sample in all surveys except that there are proportionally more males in this group of participants (17 out of 41, about 40%), compared to the full sample (17.6% being male in Survey 1, 28.3% in Survey 2 and 28.6% in Survey 3).

Table 1. Demographic characteristics of participants completing both Survey 1 and Survey 3 (N=41)

Characteristics	**n***
Status	
Persons living with IBD	41
Average years of living with IBD (Mean, SD, Range: 0-50)	19.0 (14.2)
Manitoba Index (past 3 months symptoms)	
Constantly active	3
Often active	5
Sometimes active	8
Occasionally active	7
Rarely active	14
Was well in the past 3 months	7
Age (mean, SD, range: 24-76)	52.3 (14.6)
Gender	
Female	24
Male	17
Born in Australia	34
English as main language	40
Education	
Primary school	1
High school	5
Trade certificate/TAFE/Diploma	13
University undergraduate degree	14
University postgraduate degree	8
Employment	
Full time	13
Part time	13
Not working	2
Home duties	1
Retired	10
Other	2
Residence	
Major city	33
Inner regional	5
Outer regional	2

Characteristics	n*
Remote	1
Long-standing health condition	
Crohn’s disease	23
Ulcerative colitis	17
Indeterminate colitis	1
Arthritis or joint problems	17
Lung or breathing problems	9
Back pain	12
Cancer	2
Heart problems	7
Kidney problems	3
Diabetes	2
Anxiety	7
Depression	6
Other	12

*% not reported due to sample size smaller than 100.

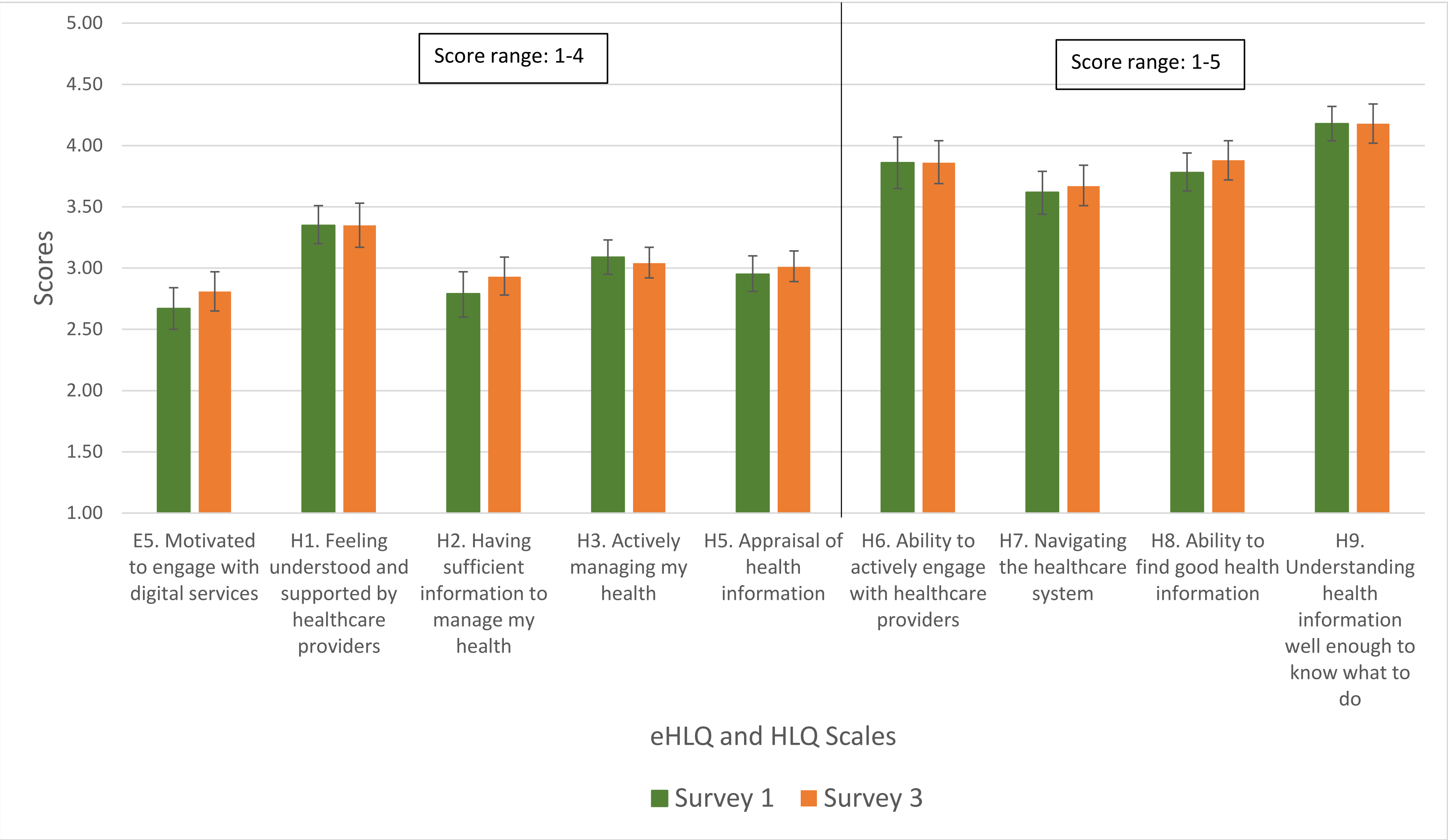
Health literacy and digital health literacy scores – Surveys 1 and 3

To compare the scores across Survey 1 and Survey 3, a paired-sample t-test was conducted. This did not find any significant differences between the scores from the two surveys, although there was a slight increase in eHLQ Scale 5 ‘Motivated to engage with digital services’ score (Survey 1: M=2.67, SD=0.55; Survey 3: M=2.81, SD=0.50) (Table 12 and Figure 4).

Table 2. Survey 1 and Survey 3 health literacy and digital health literacy scores (N=41)

	Mean (SD) [95% CI]	
Scale	**Survey 1**	**Survey 3**
Health Literacy Questionnaire (HLQ) scale		
	Score range: 1 (strongly disagree) – 4 (strongly agree)	
1. Feeling understood and supported by healthcare professionals	3.35 (0.49) [3.19-3.50]	3.35 (0.57) [3.17-3.53]
2. Having sufficient information to manage my health	2.79 (0.59) [2.61-2.98]	2.93 (0.48) [2.77-3.08]
3. Actively managing my health	3.09 (0.46) [2.95-3.23]	3.04 (0.40) [2.91-3.16]
5. Appraisal of health information	2.95 (0.45) [2.80-3.09]	3.01 (0.39) [2.88-3.13]
	Score range: 1 (cannot do or always difficult) – 5 (always easy)	
6. Ability to actively engage with healthcare professionals	3.86 (0.67) [3.65-4.07]	3.86 (0.55) [3.68-4.03]
7. Navigating the healthcare system	3.62 (0.56) [3.45-3.80]	3.67 (0.52) [3.50-3.83]
8. Ability to find good health information	3.78 (0.50) [3.62-3.93]	3.88 (0.49) [3.72-4.04]
9. Understand health information well enough to know what to do	4.18 (0.45) [4.04-4.32]	4.18 (0.50) [4.02-4.34]
eHealth Literacy Questionnaire (eHLQ) scale		
	Score range: 1 (strongly disagree) – 4 (strongly agree)	
5. Motivated to engage with digital services	2.67 (0.55) [2.50-2.84]	2.81 (0.50) [2.65-2.97]

Figure 1. Survey 1 and Survey 3 health literacy and digital health literacy scores (N=41)



Appendix 6: The Patient Education Materials Assessment Tool (PEMAT)

Resource 1: About Crohn's Disease

Understandability

Item #	Item	Response Options	Rating old website	Rating new website
Topic: Content				
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	1	1
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1	0	1
Topic: Word Choice & Style				
3	The material uses common, everyday language.	Disagree=0, Agree=1	1	1
4	Medical terms are used only to familiarise audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	1	1
5	The material uses the active voice.	Disagree=0, Agree=1	1	1
Topic: Use of Numbers				
6	Numbers appearing in the material are clear and easy to understand.	Disagree=0, Agree=1, No numbers=N/A	N/A	N/A
7	The material does not expect the user to perform calculations.	Disagree=0, Agree=1	1	1
Topic: Organisation				
8	The material breaks or "chunks" information into short sections.	Disagree=0, Agree=1, Very short material=N/A	1	1
9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material=N/A	1	1
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	0	1
11	The material provides a summary.	Disagree=0, Agree=1, Very short material=N/A	0	1
Topic: Layout & Design				
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1, Video=N/A	1	1

Topic: Use of Visual Aids				
15	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	Disagree=0, Agree=1	1	1
16	The material's visual aids reinforce rather than distract from the content.	Disagree=0, Agree=1, No visual aids=N/A	1	1
17	The material's visual aids have clear titles or captions.	Disagree=0, Agree=1, No visual aids=N/A	1	1
18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	1	1
19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	N/A	N/A
Total Points:			**12**	**15**
Total Possible Points:			**15**	**15**
Understandability Score (%): **(Total Points / Total Possible Points x 100)**			**80%**	**100%**

Actionability

Item #	**Item**	**Response Options**	**Rating old website**	**Rating new website**
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	0	1
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	0	1
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	0	0
23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	0	0
24	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=N/A	N/A	N/A
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	N/A	N/A

26	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	0	0
Total Points:			**0**	**2**
Total Possible Points:			**5**	**5**
Actionability Score (%): **(Total Points / Total Possible Points x 100)**			**0%**	**40%**

Resource 2: Travel and IBD

Understandability

Item #	Item	Response Options	Rating old website	Rating new website
Topic: Content				
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	1	1
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1	0	1
Topic: Word Choice & Style				
3	The material uses common, everyday language.	Disagree=0, Agree=1	1	1
4	Medical terms are used only to familiarise audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	1	1
5	The material uses the active voice.	Disagree=0, Agree=1	1	1
Topic: Use of Numbers				
6	Numbers appearing in the material are clear and easy to understand.	Disagree=0, Agree=1, No numbers=N/A	N/A	1
7	The material does not expect the user to perform calculations.	Disagree=0, Agree=1	1	1
Topic: Organisation				
8	The material breaks or "chunks" information into short sections.	Disagree=0, Agree=1, Very short material=N/A	1	1
9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material=N/A	1	1
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	0	1
11	The material provides a summary.	Disagree=0, Agree=1, Very short material=N/A	0	1
Topic: Layout & Design				
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1, Video=N/A	1	1
Topic: Use of Visual Aids				

15	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	Disagree=0, Agree=1	1	0
16	The material's visual aids reinforce rather than distract from the content.	Disagree=0, Agree=1, No visual aids=N/A	1	N/A
17	The material's visual aids have clear titles or captions.	Disagree=0, Agree=1, No visual aids=N/A	1	N/A
18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	1	N/A
19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	N/A	N/A
Total Points:			**12**	**12**
Total Possible Points:			**15**	**13**
Understandability Score (%): **(Total Points / Total Possible Points x 100)**			**80%**	**92%**

Actionability

Item #	**Item**	**Response Options**	**Rating old website**	**Rating new website**
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	0	1
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	0	1
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	0	1
23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	0	0
24	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=N/A	N/A	N/A
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	N/A	N/A
26	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	0	0

Total Points:	**0**	**3**
Total Possible Points:	**5**	**5**
Actionability Score (%): **(Total Points / Total Possible Points x 100)**	**0%**	**60%**

Resource 3: Working with IBD

Understandability

Item #	Item	Response Options	Rating old website	Rating new website
Topic: Content				
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	1	1
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1	1	
Topic: Word Choice & Style				
3	The material uses common, everyday language.	Disagree=0, Agree=1	1	1
4	Medical terms are used only to familiarise audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=2	1	1
5	The material uses the active voice.	Disagree=0, Agree=1	1	1
Topic: Use of Numbers				
6	Numbers appearing in the material are clear and easy to understand.	Disagree=0, Agree=1, No numbers=N/A	1	
7	The material does not expect the user to perform calculations.	Disagree=0, Agree=1	1	
Topic: Organisation				
8	The material breaks or "chunks" information into short sections.	Disagree=0, Agree=1, Very short material=N/A	1	1
9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material=N/A	1	1
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	1	1
11	The material provides a summary.	Disagree=0, Agree=1, Very short material=N/A	0	0
Topic: Layout & Design				
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1, Video=N/A	1	1

13	Text on the screen is easy to read.	Disagree=0, Agree=1, No text or all text is narrated=N/A		1
14	The material allows the user to hear the words clearly (e.g., not too fast, not garbled).	Disagree=0, Agree=1, No narration=N/A		1
Topic: Use of Visual Aids				
15	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	Disagree=0, Agree=1	0	
16	The material's visual aids reinforce rather than distract from the content.	Disagree=0, Agree=1, No visual aids=N/A	N/A	
17	The material's visual aids have clear titles or captions.	Disagree=0, Agree=1, No visual aids=N/A	N/A	
18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	N/A	1
19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	N/A	N/A
Total Points:			**13**	**11**
Total Possible Points:			**15**	**12**
Understandability Score (%): **(Total Points / Total Possible Points x 100)**			**87%**	**92%**

Actionability

Item #	**Item**	**Response Options**	**Rating old website**	**Rating new website**
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	1	1
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	1	1
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	1	1
23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	0	
24	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=N/A	N/A	

25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	N/A	N/A
26	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	0	
Total Points:			**3**	**3**
Total Possible Points:			**5**	**3**
Actionability Score (%): **(Total Points / Total Possible Points x 100)**			**60%**	**100%**