IBD GP Aware Project -

Improving GP awareness and training

Phase 1 Report

Developed by Australian General Practice Accreditation Limited (AGPAL) on behalf of Crohn's & Colitis Australia for the Commonwealth-funded GP Aware project

Contact us

☎ 1300 362 111
info@agpal.com.au
www.agpal.com.au

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1. Abbreviations

ACCRM: Australian College of Rural and Remote Medicine
AGA: American Gastroenterology Association
CCA: Crohn’s & Colitis Australia
CD: Crohn’s disease
ECCO: European Crohn’s and Colitis Organisation
eTG: Therapeutic Guidelines
GESA: Gastroenterology Society of Australia
GP: General practitioner
GPMP: General Practitioner Management Plan
IBD: Inflammatory bowel disease
PHN: Primary Health Network
RACGP: Royal Australian College of General Practitioners
UC: Ulcerative colitis

2. Background

Crohn's disease (CD) and ulcerative colitis (UC) are chronic diseases comprising periods of remission, flares and relapses which, if not well managed, have significant impact on a person's quality of life.[1] These two diseases are often collectively known as inflammatory bowel diseases (IBD). IBD is suspected to affect between 75,000 and 91,000 Australians.[2] Unfortunately, due to the challenge of integrating multidisciplinary IBD care across a variety of healthcare sectors, IBD management is often insufficient and lacks continuity.[3]

The Australian Government Department of Health reports there were 773 gastroenterology and hepatology specialists across the nation registered in 2016, including seven administrators, 730 clinicians, 11 educators, 20 researchers and five classified as other.[4] Statistics released in December 2019 about the number of Australian GPs indicate that in 2018 there were a total of 36,938 GPs nationally (i.e. 25,149 FTE) distributed across metropolitan, regional, rural and remote areas.[5] Optimal care typically needs to involve other specialists and allied health professionals in coordinated team-based and shared care arrangements to ensure patients achieve best health outcomes. These other specialists and allied health professionals may include paediatricians, obstetricians, physiotherapists, dietitians, psychologists, IBD nurses and health coaches. Access to GPs, allied health and specialist services diminishes as geographical remoteness increases.

Runicman et al.[6] suggest that, generically, appropriate care (i.e. care in line with evidence-based or consensus-based guidelines) is received in 57 per cent of healthcare encounters, whether they be in hospital or community-based settings. They identified that while 'there were pockets of excellence and some aspects of care were well managed across health care providers' (i.e. transitions of care) there was room for improvement.[6]

In recognising the need to strengthen evidence-based care, the Gastroenterology Society of Australia (GESA) released a clinical update for GPs and physicians in 2018 which had a diverse range of IBD referral and management guidelines.[7] Crohn's & Colitis Australia (CCA) performed a literature review highlighting matters within IBD care that were inadequate and required improvement.[8] Issues identified in the CCA review were a lack of clear GP referral guidelines and protocols, and that GP IBD knowledge was subpar as a result of the difficulty in IBD diagnosis, lack of clear guidelines, guideline adherence, and poor referral quality.

CCA's 2018 Stocktake of Inflammatory Bowel Disease Health Improvement Activities[9] identified guidelines, protocols and improvement related actions across numerous organisations within Australia, including:

- guidelines by the Australian IBD Consensus Working Group through Concord Hospital NSW with CD and UC specific consensus statements published in 2015

- a Clinical Prioritisation Criteria decision support tool (Home | Clinical Prioritisation Criteria (health.qld.gov.au)) for the whole of Queensland, developed and published by Queensland Health
- a Queensland Health-initiated General Practitioner with a Special Interest (GPwSI) program, which was to be rolled out across the state
- CCA assessment of quality of care from a patient perspective
- a Queensland Health-initiated state-wide IBD specific HealthPathways online manual for primary and specialist services
- face-to-face and eLearning that involved IBD, initiated by the Royal Australian College of General Practitioners (RACGP)
- local guidelines for managing UC and information pamphlets for patients to improve their overall IBD management, published by Lyell McEwin Hospital in Northern Adelaide
- clear GP referral protocols and guidelines by Royal Adelaide Hospital/Central Adelaide Local Health Network (LHN) in conjunction with GESA's sponsored e-tool IBS4GPs. This tool was also to be launched at Australian Gastroenterology Week in Brisbane 2018.

While Australia has tried to improve IBD referral guidelines and management, it's questionable whether these initiatives have solidified within primary healthcare. A significant issue in IBD management and best care revolves around:

- how practitioners and the public engage with the current clinical guidelines
- how these guidelines are interpreted to individual needs
- whether these guidelines are commonly known about, utilised and accessed
- whether these guidelines are applied and performed accordingly by practitioners or whether practitioners deviate from the management guidelines as they see fit.[8]

3. Inflammatory Bowel Disease (IBD) GP Aware project

The Inflammatory Bowel Disease National Awareness Action Plan,[10] launched in 2019, emphasises the need to improve awareness, management and referral of people living with inflammatory bowel disease (IBD). In response to this finding, Crohn's & Colitis Australia (CCA) recently secured Commonwealth Department of Health funding for education and awareness-raising activities that align with recommended actions in the IBD National Awareness Action Plan, specifically Priority Area 3 (*Support general practitioners to more effectively participate in IBD management*). The grant's objective is to support the recommended activities of the Action Plan, including to *Improve GP capacity to support IBD patients through awareness, education and continuing professional development (CPD)*.

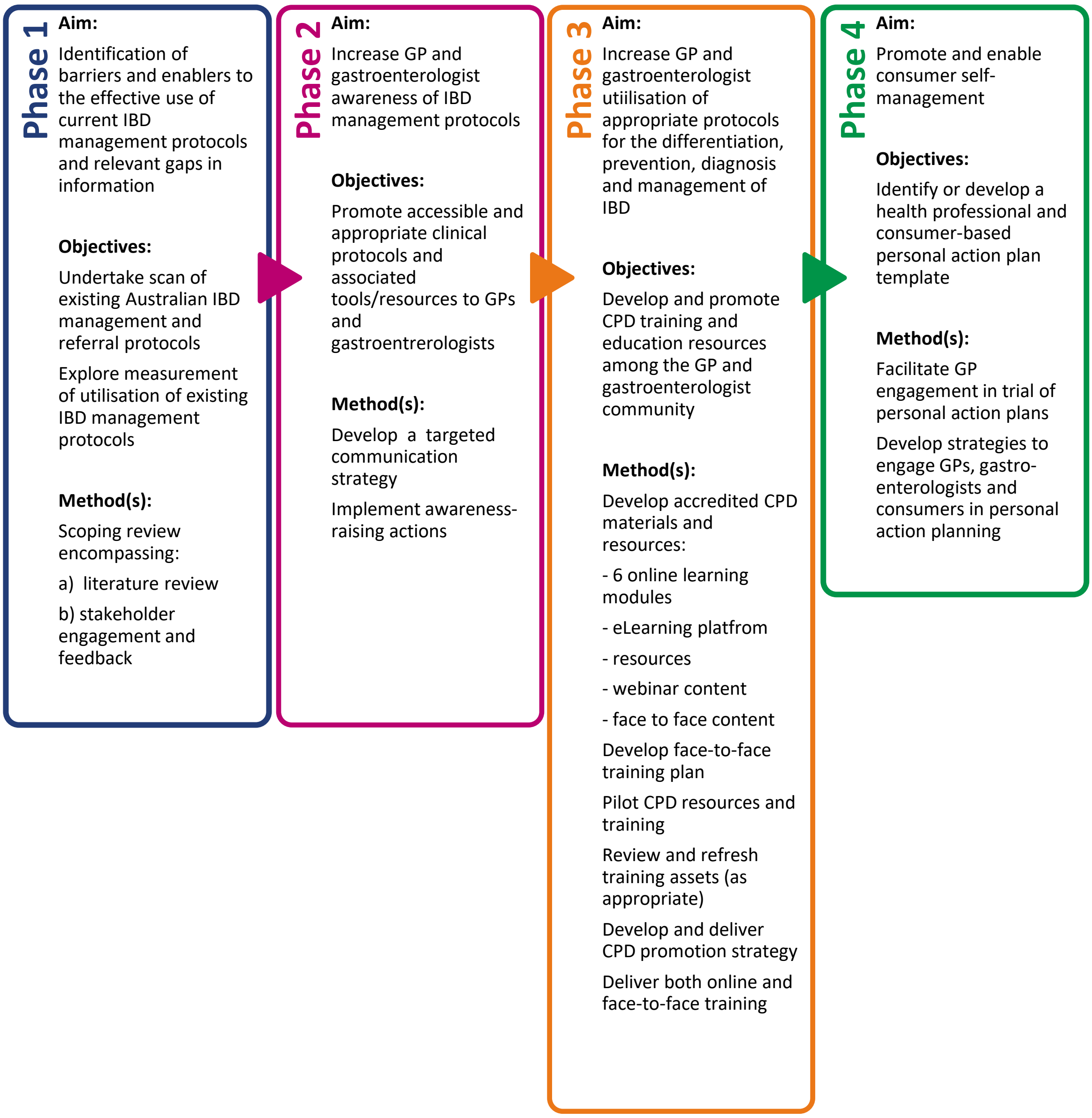
The goal of the Inflammatory Bowel Disease (IBD) GP Aware project is to provide better quality care to all patients, regardless of setting – right care, at the right time, in the right place, provided by the right person, at the right cost – and in doing so, promote value-based healthcare: optimal health outcomes and experience of care, supportive and skilled workforce, and best value care.

The IBD GP Aware project aims to:

- design and implement a campaign to promote existing health practitioner guidelines for IBD management
- develop IBD-specific CPD for GPs and generalist gastroenterologists (GEs)
- develop and promote the use of individual care plans for IBD management in primary and specialist care settings
- collect data that monitors and evaluates the utilisation of resources.

CCA, GESA and AGPAL are adopting a developmental and phased approach to this initiative (Figure 1). AGPAL is proud to be partnering with CCA and GESA to co-design and develop IBD training resources for the IBD GP Aware project.

IBD GP Aware project



Phase 1

Aim:

Identification of barriers and enablers to the effective use of current IBD management protocols and relevant gaps in information

Objectives:

Undertake scan of existing Australian IBD management and referral protocols

Explore measurement of utilisation of existing IBD management protocols

Method(s):

Scoping review encompassing:

a) literature review

b) stakeholder engagement and feedback

Phase 2

Aim:

Increase GP and gastroenterologist awareness of IBD management protocols

Objectives:

Promote accessible and appropriate clinical protocols and associated tools/resources to GPs and gastroentrerologists

Method(s):

Develop a targeted communication strategy

Implement awareness-raising actions

Phase 3

Aim:

Increase GP and gastroenterologist utiilisation of appropriate protocols for the differentiation, prevention, diagnosis and management of IBD

Objectives:

Develop and promote CPD training and education resources among the GP and gastroenterologist community

Method(s):

Develop accredited CPD materials and resources:

- 6 online learning modules
- eLearning platfrom
- resources
- webinar content
- face to face content

Develop face-to-face training plan

Pilot CPD resources and training

Review and refresh training assets (as appropriate)

Develop and deliver CPD promotion strategy

Deliver both online and face-to-face training

Phase 4

Aim:

Promote and enable consumer self-management

Objectives:

Identify or develop a health professional and consumer-based personal action plan template

Method(s):

Facilitate GP engagement in trial of personal action plans

Develop strategies to engage GPs, gastro-enterologists and consumers in personal action planning

Figure 1: Overview – IBD GP Aware project.

Source: Developed by AGPAL on behalf of CCA.

4. Methods and approach

As shown in Figure 1, Phase 1 of the IBD GP Aware project comprises:

a) a desktop review of IBD and related guidelines, grey and black literature about IBD and related guidelines, and the utilisation of these guidelines

b) stakeholder engagement encompassing direct feedback from GPs and generalist GEs about their awareness of and preferences for IBD guidelines, access and utilisation, health literacy, CPD needs, and education and training preferences.

Phase 1 (a) of the project concluded with the publication of the literature review results in November 2020.[11] The literature review ascertained existing Australian IBD management and referral protocols, and established learnings on the utilisation of such resources. The report includes international equivalents identified during the search.

The literature review results informed the Phase 1 (b) stakeholder engagement activity. With this activity, the review team sought to garner direct feedback from GPs and generalist GEs to help inform and shape the development of an IBD guideline communication and marketing campaign and the development of tailored CPD and associated educational materials, tools and resources.

4.1. Recruitment

The review team invited GPs and generalist GEs to participate in stakeholder engagement activity:

- AGPAL reached out across its key stakeholder, general practice and GP networks to recruit GPs and generalist GEs.
- GESA used its provider networks to recruit generalist GEs.

Initially the review team intended to include only generalist GEs in the scope of the engagement activity, but specialist GEs (i.e. gastroenterologists with a special interest in IBD) were keen to be involved. The team therefore broadened the scope so specialist GEs could participate.

Appendix 1 has the expression of interest (EOI) and Appendix 2 has the participant information and consent form which the review team used for this engagement activity.

4.2. Stakeholder engagement

The review team engaged stakeholders via a mixed method approach comprising:

- a preliminary survey (20 minutes maximum) (Appendices 3 and 4), which the team sent to a personal email address and participants completed online via Survey Monkey (see Appendix 5a,b)
- 1.5 hour online focus groups held amongst peers (other GPs and generalist GEs)
- a final survey (10 minutes maximum) (Appendix 6), which the review team also sent to a personal email address and participants completed online via Survey Monkey (see Appendix 7).

To help overcome the inherent challenge of clinician availability, the review team also offered an opportunity to participate in a 30-minute one-on-one semi-structured interview to those GPs and GEs (generalist or specialist) who were keen to participate but unable to attend the scheduled focus groups.

All participants were encouraged to complete all components of the engagement activity (Figure 2).

The review team provided all participants, regardless of level of engagement, with a $100 gift voucher as a small recognition of their contribution.

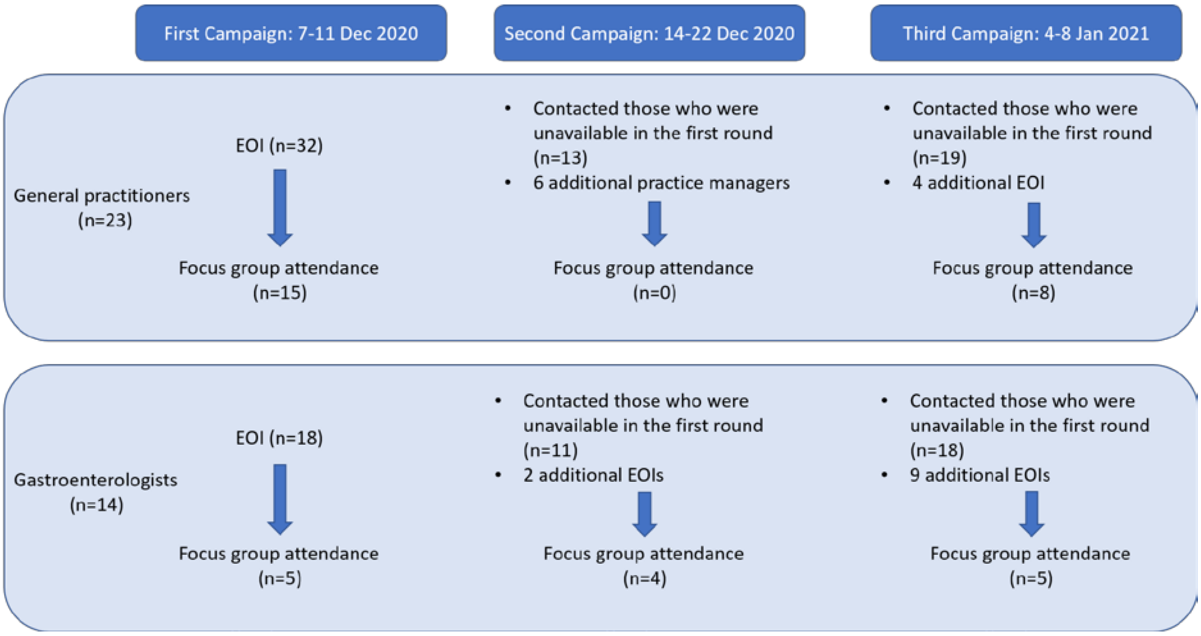


Figure 2: IBD GP Aware project Phase 1 engagement activity.
Source: Developed by AGPAL on behalf of CCA.

4.3. Data quality and management

All feedback provided is managed in accordance with Australian Privacy Principles (AAP) 2014 (available at https://www.oaic.gov.au/privacy/australian-privacy-principles/) and anonymised, collated and considered on a thematic basis.

5. Results and discussion

The following summarises the results of the GP and GE preliminary surveys and the focus group/semi-structured interview activity, plus feedback received from both groups in the final survey.

5.1. General Practitioners

5.1.1. Engagement, demographics and activity

The review team collected a total of 26 responses to the **preliminary survey**, consisting of 84.6% (n=22) GPs, 7.7% (n=2) GP supervisors and 7.7% (n=2) GP registrars. When asked about their service type, 88.5% (n=23) of participants said ‘mainstream’, 11.5% (n=3) noted ‘GPs with a special interest’, 11.5% (n=3) said ‘Aboriginal Community Controlled Health Services’ and 3.9% said ‘afterhours GP’. The length of practice ranged from three weeks to 40 years, with a mean of 16.6 years (SD 12.0), and the most common lengths of practice were equally five and 14 years (n=3). Location varied for participants: 59% (n=13) from New South Wales, 27% (n=6) from Queensland and 14% (n=3) from Victoria. Predominantly females completed the preliminary survey (68.2%; n= 15). Participant age ranged from 30 to 70 years old, with the average age being 47.76 years.

In terms of general patient engagement, participants identified a range between 30 and 1000 patients consulted per month. Of those, between zero and 21 patients had IBD and zero to eight were classified with either UC or CD, per month (Table 1).

	Total number of patients	Total number of patients with IBD	Total number of patients with UC	Total number of patients with CD
Min–max	30–1000	0–21	0–8	0–8
Average (±SD)	304.16 (216.8)	5.27 (5.3)	2.23 (2.0)	1.88 (1.6)
Mode	250	2	1	1

Table 1: Patient engagement figures among participating GPs per month.
Source: Developed by AGPAL on behalf of CCA.

Of the 26 participants to the preliminary survey, 23 GPs went on to participate in a focus group or a one-on-one semi-structured interview.

5.1.2. Clinical guidelines: awareness, utilisation, preferences and useability

5.1.2.1. Preliminary survey results

Results from the preliminary survey identified key themes on:

- access and utilisation of IBD guidelines
- seeking support and advice from allied health
- how to increase IBD guideline awareness
- preferences for IBD guideline use
- general engagement preferences for using IBD guidelines.

Access and utilisation of IBD guidelines

Participants said they accessed IBD guidelines in these ways:

- online (n=15)
- specialist correspondence (n=3)
- electronic therapeutic guidelines (n=3)
- Google (n=3)
- RACGP (n=3)
- subscriptions (n=3)
- phone (n=2)
- previous knowledge (n=1)
- computer (n=1)
- post (n=1)
- newsletter (n=1).

According to the preliminary results, the participants use these IBD guidelines: British Society of Gastroenterology (BSG) consensus guidelines (n=1), Crohn's & Colitis Australia (CCA) (n=1), Therapeutic Guidelines (n=2), GESA (n= 6), HNE (n=1) and RACGP (n= 3).

Interestingly, 44% of participants said they did not refer to any guideline for IBD management.

Participants were asked to identity their awareness and utilisation of each of 34 online IBD guidelines, fact sheets and protocols (Figure 3; Supplementary Table 1). Figure 3 gives an overview of responses, per source document.

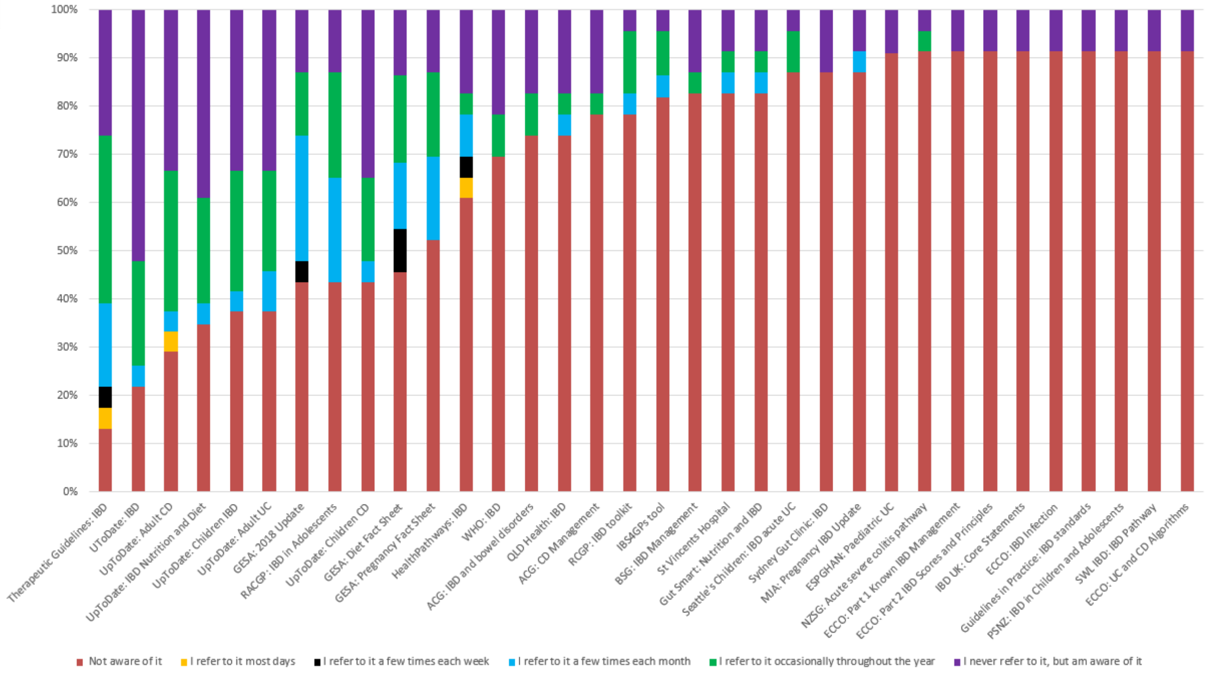


Figure 3: IBD clinical guideline awareness and utilisation among participating GPs.
Source: Developed by AGPAL on behalf of CCA.

Allied health support

The preliminary survey asked how often participants seek advice from specialists. For patients with new symptoms of IBD, 43.5% of participants responded ‘always’, 34.8% responded ‘usually’, 4.4% said ‘sometimes’ and 8.7% said ‘rarely’ (Figure 4). No GP said they never seek specialist advice for these patients. For patients with known IBD diagnosis presenting with symptoms, 17.4% responded ‘always’, 39.1% said ‘usually’, 30.4% responded ‘sometimes’, 4.4% said ‘rarely’ and 4.4% said ‘never’ (Figure 4).

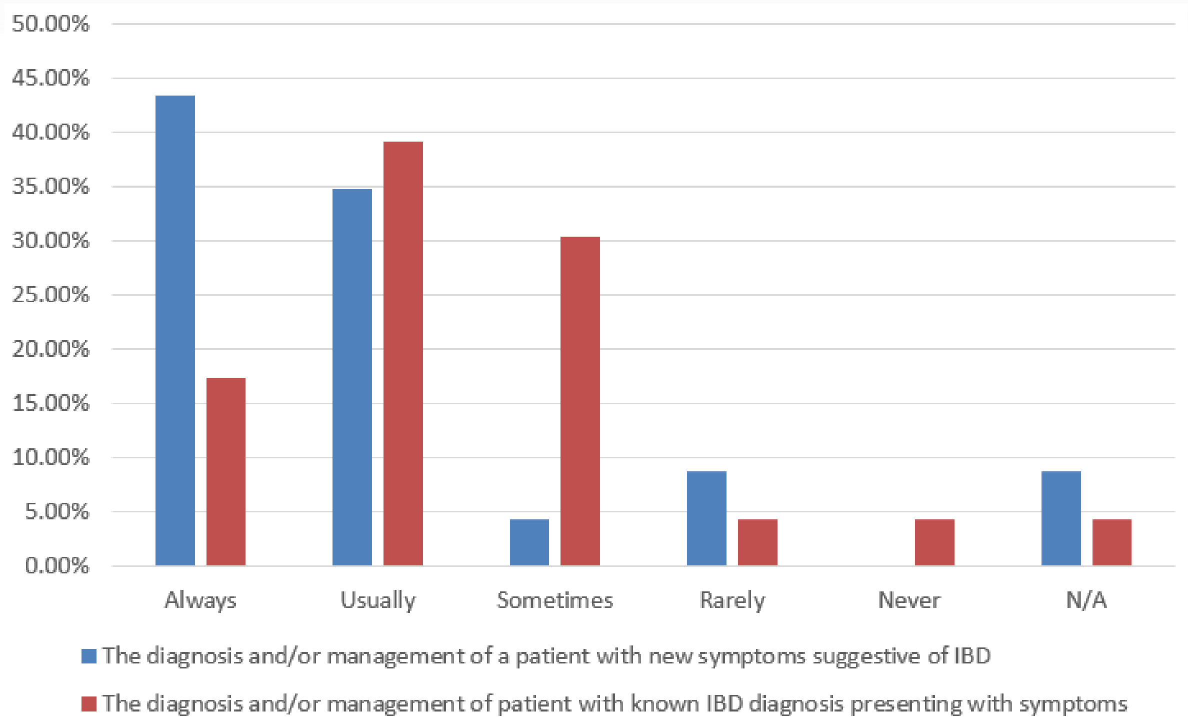


Figure 4: How often GPs seek advice from specialists for IBD patients.
Source: Developed by AGPAL on behalf of CCA.

Participants also specified the frequency of allied health engagement (Table 2), indicating that:

- they typically never refer to a pharmacist, physiotherapist, exercise physiologist or psychiatrist
- they either always or usually refer to a dietitian
- they sometimes refer to a psychologist.

Allied health	**Always**	**Usually**	**Sometimes**	**Rarely**	**Never**
Pharmacist	0%	13.6%	13.6%	31.8%	40.9%
Dietician	30.4%	30.4%	26.1%	4.4%	8.7%
Physiotherapist	0%	0%	22.7%	36.4%	40.9%
Exercise physiologist	4.6%	0%	27.3%	22.7%	45.5%
Psychologist	9.1%	9.1%	50.0%	9.1%	22.7%
Psychiatrist	0%	0%	13.6%	40.9%	45.5%

Table 2: Participating GP allied health referrals.
Source: Developed by AGPAL on behalf of CCA.

Suggestions for increasing awareness of IBD guidelines

Participants identified many ways to raise awareness of IBD guidelines:

- hosting or linking educational and training webinars and including resources on professional body and accreditation sites e.g. GESA/RACGP/ACRRM
- giving participants hard copies of guidelines and encouraging them to store them in their practice
- making available and encouraging GPs to read the latest research and publications on IBD
- having GEs send correspondence to and liaise with GPs about the guidelines
- including links to specific guidelines and the local pathway information in current software (such as eTG and HealthPathways)
- publishing streamlined information for GPs in a single consensus document or pathway with quickly accessible highlights
- promoting a select number of guidelines through:
    - PHN advertising
    - direct contact with GPs
    - media promotion
    - Australian Journal of General Practice.

Preferences for IBD guidelines

According to the preliminary survey, the top three GP-preferred IBD guidelines are:

1. therapeutic guidelines
2. the clinical update for GPs and practitioners for IBD by GESA
3. the diet IBD fact sheet by GESA (Figure 5).

When participants were asked why they preferred these guidelines, four themes emerged:

1. accessibility – easy to use and localised
2. awareness – familiar; used for other clinical presentations; do not know of other guidelines
3. content – easy to read, generalised, to the point, and a single source of information
4. importance – confidence in these guidelines being regularly reviewed and a trusted source of information relevant to the needs of Australians; used specifically for prescribing and, if additional information or details are needed, alternative guidelines are sought.

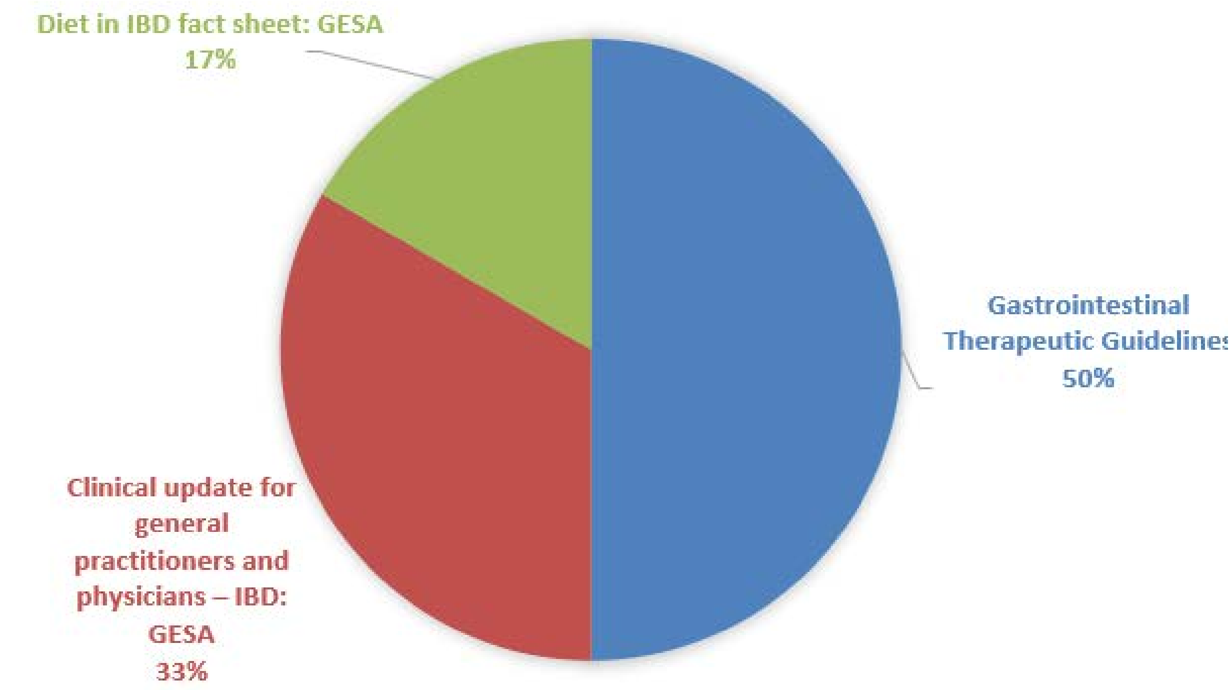


Figure 5: Top three GP-preferred IBD guidelines.
Source: Developed by AGPAL on behalf of CCA.

Useability of IBD guidelines

GPs were asked in the preliminary survey how they would generally access IBD guidelines. Access via clinical standards related websites was the most popular response, and via Australian professional body websites rated second (Figure 6). When asked what tools they use to access IBD guidelines, GPs reported the top three as HealthPathways, a general Google search or Google Scholar, and UpToDate respectively (Figure 7).

Common responses to what participants like about the accessibility of these guidelines were that they are easy and quick to access, free, easy to navigate, familiar and trusted, and contribute to education credit (Table 3). Participants wished they could improve the guidelines' approach (more streamlined) and clarity, be offered more frequent updates, and be made more aware of them (Table 3). Suggestions for increasing awareness, access and utilisation of IBD guidelines (Table 3) are to:

- increase communication between specialists and allied health
- incorporate the guidelines into GP training
- make summaries
- have a single centralised Australian IBD body
- create printable and simple charts
- increase promotion of the guidelines.

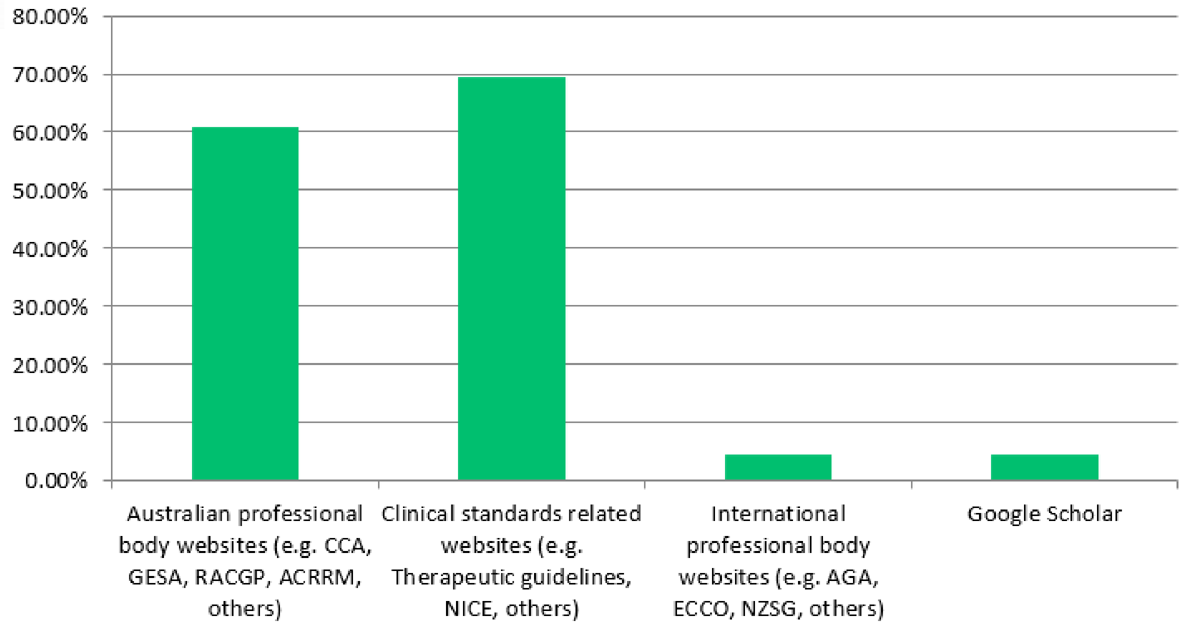


Figure 6: How GPs access IBD guidelines.

Source: Developed by AGPAL on behalf of CCA.

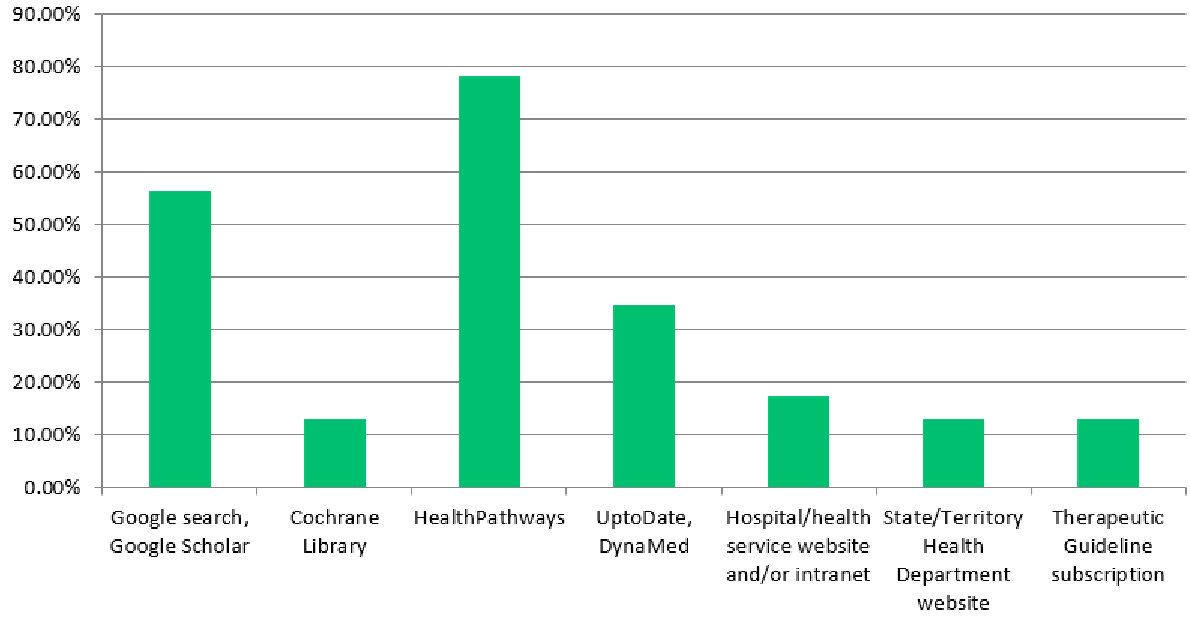


Figure 7: Online tools GPs use to access IBD guidelines.

Source: Developed by AGPAL on behalf of CCA.

I like ...	I wish ...	Suggestions
Quick access to information	Clarity	Increased communication with specialists and allied health
Contributes to education credit	Free access	Incorporate into training
Easy access	Increased awareness	Printable and simple charts
Easy to navigate	Streamlined approach	Promotion
Familiar	Frequent updates	Single centralised Australian IBD body
Free		Summaries
Trusted		

Table 3: GPs preferences and suggestions for the accessibility of IBD guidelines.
Source: Developed by AGPAL on behalf of CCA.

Regarding guideline use, overall, participants found the guidelines easy to use (Figure 8) as a result of:

- access – generally quick and easy to use because often the software or guideline is already on desktop
- clarity – clear and succinct information presented in a simple language and process
- format – familiar and easy layout
- relevance – provide information relevant to GPs and different clinical presentations.

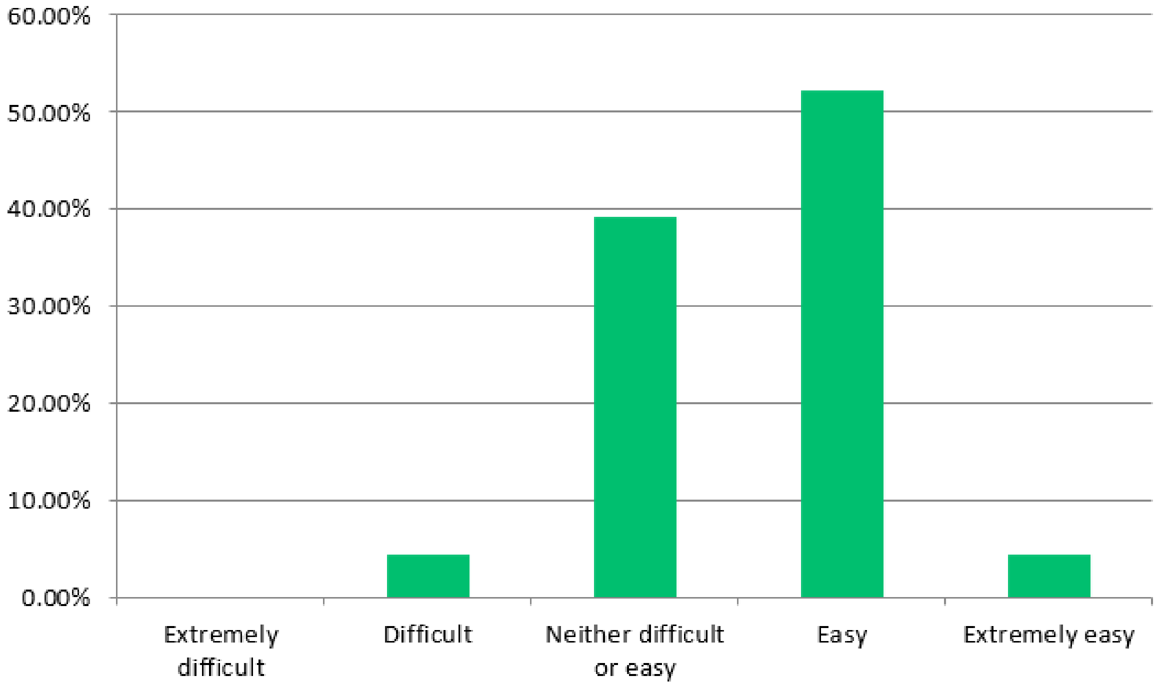


Figure 8: GPs' thoughts on how easy the guidelines are to use.
Source: Developed by AGPAL on behalf of CCA.

Participant suggestions for improving useability of guidelines include:

- access – make it easier to obtain resources (e.g. no password requirements)
- communication – add tools that would allow better communication between specialists and GPs, contact information for a point of contact, and patient education material
- format – design a simple and visually easy layout and a streamlined approach with search bar and interactive flowcharts/algorithms, with both a HTML and PFD format and guidelines specifically for GPs.

GPs were asked to comment on factors relating to guideline use for education and training. Suggestions include having specific guidelines for GPs but with GPs involved in developing them. They saw this GP involvement as essential so the guidelines could be relevant and achievable in the GP setting since GPs are short on time for CPD. Promoting the resources and making them streamlined were both important to participants, as making the resources easy to find and use. Capturing patient facts and making the resources available to patients are other suggestions.

5.1.2.2. Focus group/semi-structured interviews

The preliminary survey trends and themes around clinical guidelines awareness, utilisation and useability prompted focus group and semi-structured interview questions. Three significant topics emerged during these interviews:

1. clinical guidelines and how GPs access them and why
2. diagnosis and management of IBD
3. multidisciplinary teams/shared care.

Clinical guidelines that GPs use

> *'I think as a general practitioner, I hear my colleagues. I find that people come to me as a sort of acute emergency because they cannot see the specialist now. And they want someone to be managing their acute bleeding, for example, or acute pain. And the only option we have is to give them steroids, rectal steroids or enema steroids, or steroid tablets, or Mezavant®. So, what we do is manage acute presentations and emergency presentations.'*

Feedback from GPs corroborated survey results on the awareness and utilisation of IBD guidelines:

- newly qualified GPs will typically refer to training manuals, textbooks and resources for guidance (e.g. Harrison's Principles of Internal Medicine and the Yamada Textbook of Gastroenterology were mentioned), noting that these are not freely available online.
- there was also evidence of longstanding GPs still using the hard copy textbooks and manuals that they used in training, although they recognise that guidelines may have moved on.
- their main points of reference include:
    - Australian Guidelines for General Practitioners and Physicians – Inflammatory Bowel Disease, 4th Edition (updated 2018), GESA
    - eTG guidelines on Inflammatory Bowel Disease (available via subscription)
    - RACGP resources, such as:

        - Australian Journal of General Practice (AJGP) which includes peer reviewed articles
        - RACGP check program (an independent learning program delivered by RACGP) and associated resources
        - RACGP papers and publications (typically included as an insert in the AJGP) on IBS, IBD, Crohn’s and colitis
    - UpToDate – an online clinical decision support resource, available via subscription.

Additional guidelines and resources identified during discussions include the Aspen Physicians’ Crohn’s Disease Annual Cycle of Care Plan. The GP who mentioned this freely available tool advised that he had adapted it for colitis type patients and utilised to inform the development of a General Practitioner Management Plan (GPMP) for his patients. He recognised that all IBD patients had comorbidity including youth who may have an eating disorder resulting from ill-informed attempts at self-managing the condition.

Factors that typically inform a GP’s choice of which IBD guideline to use include (Figure 9):

- familiar – accustomed to a certain structure and content and so find it easier to use
- contemporary – published within the last three years or so
- comprehensive – address in a clear and succinct manner clinical questions about the diagnosis and management of IBD, prevention requirements (e.g. appropriate vaccination regime) and the use of medications (e.g. steroids, and less so biologics and synthbiologics which are considered the clinical domain of specialists)
- Australian focused – where possible, guidelines reflect the GP scope of license and use of available medications (although GP participants are interested in advances made across the rest of the world, such as in New Zealand, the United States, the United Kingdom, Europe and Canada).

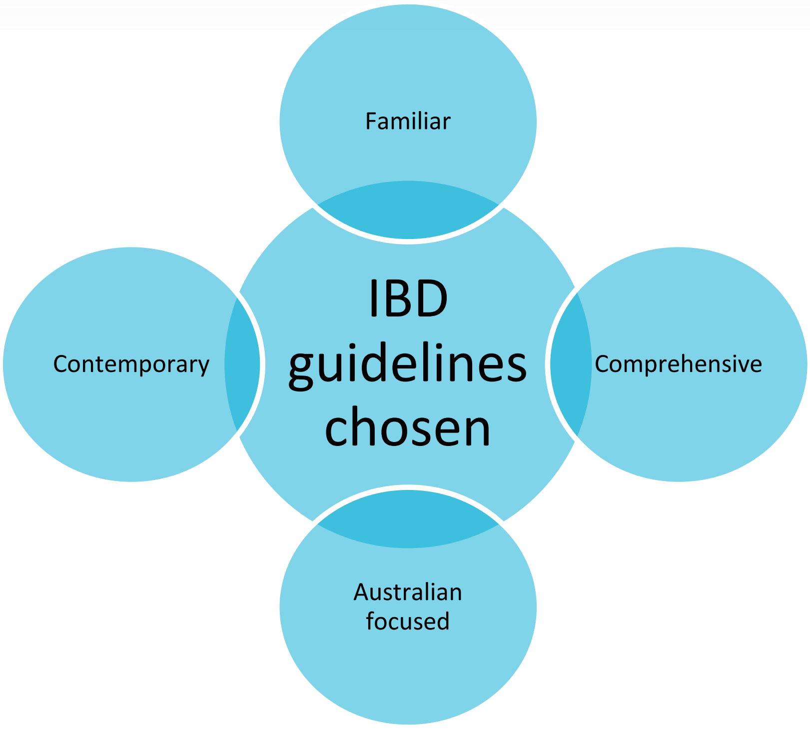


Figure 9: Factors that inform GPs' choice of IBD guidelines.
Source: Developed by AGPAL on behalf of CCA.

GPs said they typically access IBD guidelines via:

- a Google search – some have shortcut links saved on their personal computer
- HealthPathways (see text box below)
- computers and increasingly smartphones and devices (which highlights the need to ensure online resources are mobile compatible).

HealthPathways

HealthPathways is an initiative from the Canterbury District Health Board in Christchurch, New Zealand, which provides a 'whole of system' approach to effective integration of primary and acute health care services.

HealthPathways provides a secure web-based portal to GPs and other clinicians, which has information about patient assessment, management and referral pathways to help clinicians to navigate patients through the complex primary, community and acute health care systems.

All 31 Primary Health Networks (PHNs) have adopted HealthPathways, which now has the potential to reach all GPs and practice nurses, allied health and specialists, community and hospital-based staff (public or private) across Australia.

Each PHN, in collaboration with its Local Health District (LHD), adopts a prioritised approach to developing and localising clinical health pathways. In this regard there is no standard content or 'one size fits all approach'.

Feedback from GPs illustrates the different approaches to HealthPathways development:

- not localised – NZ IBD guidelines; no details on local referral pathways
- unsuccessful
- partially localised/developed – may contain links to GESA IBD guidelines and some referral pathways (typically public service only)
- fully developed/localised – a summary of clinical guidelines, links to GESA and other IBD guidelines, CCA, tools and resources (e.g. patient information sheets), referral pathways (public and private).

Participants reported that modern technology allows them to access multiple sites to address their information needs, compare information, support clinical decision-making or validate a particular course of action.

GPs feel that online versions of IBD guidelines with the following features are easy to use in a real-time consult with patients (Figure 10):

- clear and logical structure with a logical sequence/chronology that follows the patient journey, facilitated by clear menus and easy navigation; for example, sorted by:
    - risk factors and symptoms (e.g. cancer screening)
    - patient cohorts (e.g. paediatrics, youth, adults, older people, pre-conception and maternity, immunosuppressed)
    - disease trajectory (e.g. early identification, diagnosis, management–controlled, management–acute flare etc.)

  - common comorbidity (e.g. eating disorder and/or malnutrition, issues relating to psychosocial, bone density, liver function, immunosuppression etc.)
- simple dot point formats and white paper (see guidelines/standards on quality online publications/materials)
- succinct summaries (online and downloadable) with key points and messages
- capability to link across guideline content and return to the starting point
- keyword search (and typo correction) and closest related results rather than no results
- references provided in online materials with associated links, to allow the reader to undertake a deeper dive into the topic if necessary.

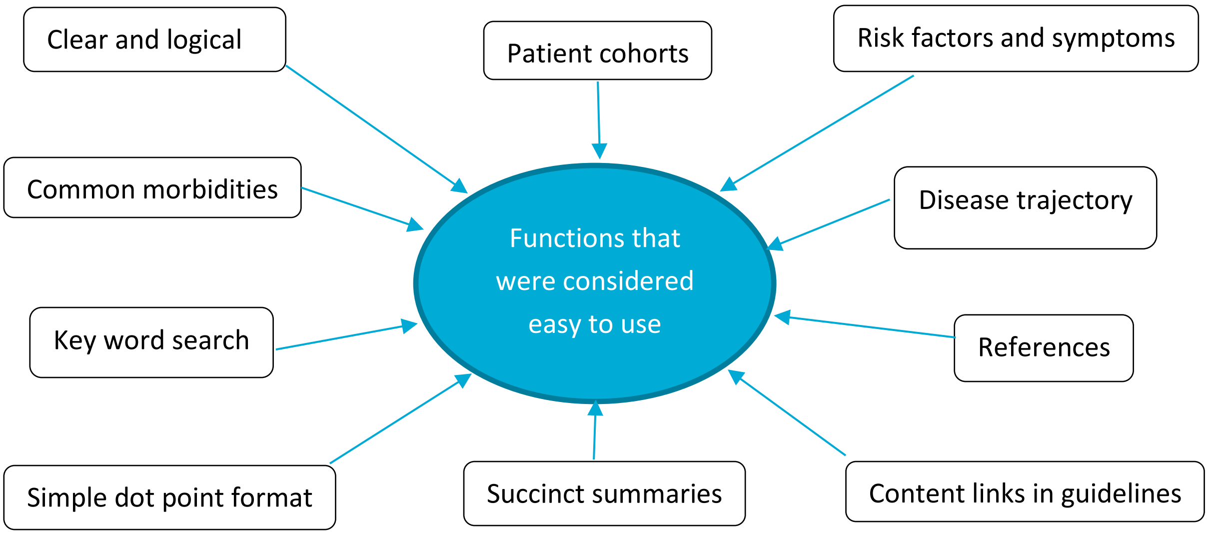


Figure 10: Features of online IBD guidelines that GPs find easy to use.
Source: Developed by AGPAL on behalf of CCA.

GPs from New South Wales mentioned the Clinical Information Access Portal which provides clinical information to the NSW public health system to support evidence-based practice at the point of care. The portal also gives access to eTG, UpToDate, Cochrane Library and so on.

Given the time constraints plaguing general practice, GPs reported that they prefer to use easily accessible platforms (e.g. eTG, UpToDate, HealthPathways etc.) which are '*constantly used for other things'* (e.g. when seeking guidelines on other clinical conditions). When the GP accesses relevant guidelines and resources, they may choose to share those resources with the patient.

Some but not all GPs are aware of resources within their clinical software system (e.g. Medical Director). Some GPs are reluctant to utilise these resources because they don't think they're credible (e.g. those sponsored by pharmaceutical companies).

GPs feel some resources are missing, including (Figure 11):

- summaries, to reduce the length and make them more useful for a 15-minute consult (Note: GPs seem reluctant to ask a patient to come back for a follow-up appointment and use the time between visits to more thoroughly review clinical guidelines, although some do)
- algorithms (i.e. if this, then do that)
- decision support tools (e.g. decision trees/flow charts (possibly interactive), to inform:
    - both GP and patient decision-making (e.g. when to refer)
    - clinical manifestations
    - options appraisals (what's next?)
    - when to refer to a GE/specialist in IBD
    - the clinical diagnostics and prework required to support a quality referral
    - the identification and management of red flags and when to escalate to a GE/specialist in IBD
- cycles of care and associated checklists, such as the Aspen Physicians' Crohn's Disease Cycle of Care
- referral checklists detailing information required in a quality referral and interoperability with smart referrals (e-referrals)
- updates on contemporary research and practice
- a central repository/archive of related papers and publications containing actual papers or links to papers, appropriately referenced
- information on '*how to access local services, whether or not they are public or private'.*

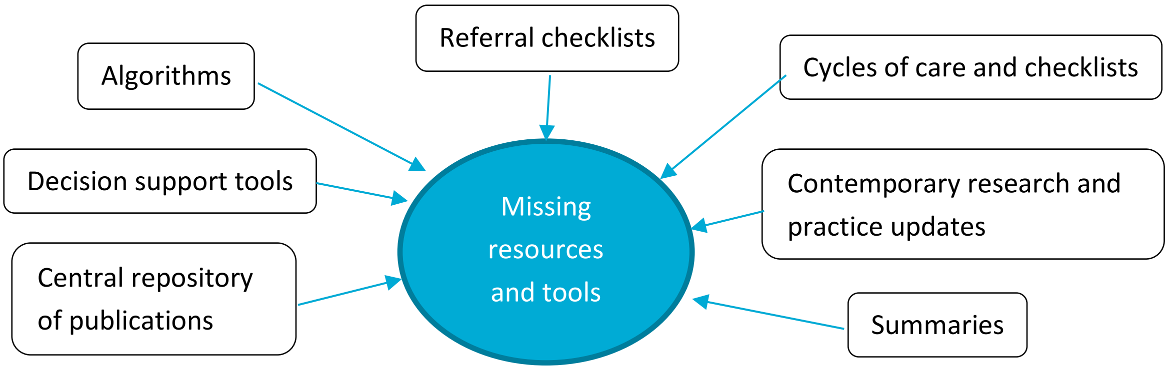


Figure 11: Resources missing from existing IBD guidelines according to GP participants.
Source: Developed by AGPAL on behalf of CCA.

Table 4 summaries the factors that either enable or constrain the use of IBD guidelines in the general practice setting.

Enabling factors	**Constraining factors**
N/A	The limited number of IBD type patients and a focus on high prevalence conditions
GP commitment to high quality patient care and concerns for patient wellbeing	15-minute medicine and the lack of time to review often quite lengthy and text heavy guidelines
Multiplicity of resources available	Patient demand and the lack of time between consultations to review guidelines and work out options and next steps
Patient feedback and guidance on IBD management often sourced from a gastroenterologist/IBD specialist	Patient feedback and guidance on IBD management often sourced from a gastroenterologist/IBD specialist

Table 4: Enabling and restraining factors for IBD guideline use among GP participants.
Source: Developed by AGPAL on behalf of CCA.

Interestingly, some GPs mentioned that while they do have a few IBD type patients 'on their books' they do not use IBD (or in some cases any) clinical guidelines to inform clinical decision-making and appropriate next steps in the diagnosis or management of patients. (Note: This reflects the survey results which demonstrated that 44% of GP participants did not use IBD clinical guidelines.) When queried why this is the case, responses included:

- *'I don't have, I haven't really had a lot of patients with Crohn's or IBD; I mean I have a handful at any given time – I haven't felt the need to look it up very often.'*
- *'You'd need to convince me that I was doing something wrong.'*

Diagnosis and management of IBD

On the whole, the diagnosis and management of IBD is considered challenging in the general practice setting, with GPs reporting that they often refer or defer to specialists for the management of these types of patient.

Urban/metropolitan GPs reported that it is easy to adopt a 'phone a friend' approach:

- *'I tend to offload them fairly quickly. I'm glad I live in the city.'*
- *'It's not difficult to access advice from public tertiary services (e.g. specialist IBD services, specialist gastroenterologists and/or an IBD nurse)':*
    - *'It's good to know you've got an on-call specialist.'*
    - *'[If you can't get the specialist] there's always GP Liaison.'*
    - *'And you might not be able to, let's say, speak to their specialist, but at least you will have a chat with a registrar and most of the time they're very useful.'*
- *'You can seek advice from a private specialist as they are considered accessible as 'their referrals depended on it'*

- refer a patient to a private specialist, *'it's not really hard to get to the specialist if the people, the patient can pay and the specialist is available.'*

The following illustrates the reasons why a GP would often adopt this approach if it was open to them:

'Most of the time comes in the management [of these patients]; for example, I don't know what will be the next steps and I have tried the first line...I've tried it and I'm not sure which second one I'll try. Which one should I choose? Or should I change the dosage of the medication? Something like that. I just give them a call and have a chat with them and most of the they will give me… some good advice, and what sort of investigation should I let's say, choose for the next step'.

Rural GPs commented on the limited access to visiting specialist services: *'They're not here all the time but you know [they'll be here] every fortnight'.* Remote GPs commented on the lack of access to specialist services (public or private). (Note: In our very small sample, we did not find the rurality of the GP to be an indicator of whether they utilised evidence-based clinical guidelines for the management of patients.)

All types of GP mentioned that cost of care, direct out-of-pocket expenses and opportunity cost are barriers to care for low SES patients. Waiting lists/times in the public sector are also a barrier: *'On the public health side, the greatest issue is still wait lists. It can be a challenge to get the patient three hours down to Melbourne. But the bigger issue is generally that they're waiting somewhere between six and 12 months for that initial hookup and 6-8 weeks in the private [system]'*. This situation clearly presents challenges to GPs for the appropriate management of patients in the intervening period: *'Do you put them on steroids or not?'*

GP participants seemed to recognise that the number of IBD patients is increasing and there may be a growing need to ensure all GPs are familiar with best practice guidelines.

GPs reported that evidence and guidance on the diagnosis, prevention and management of IBD are continually growing and it is a challenge to keep up to date with the latest evidence base or best practice. They noted the challenges of ensuring clinical guidelines are up to date and relevant, and they welcomed 'one source of truth' – that is, a regularly reviewed and up-to-date set of national guidelines to support the management of IBD patients in the general practice setting, sitting alongside a suite of contemporary and clearly categorised publications on current research projects and associated results.

Multidisciplinary teams and shared care

Discussion on the use of clinical guidelines often led to conversations about multidisciplinary team-based care and the concept of shared care.

All GPs recognised the need for a robust multidisciplinary team-based care approach but mentioned the challenges of this in practice. For example, when a GP refers a patient to a specialist, they often assume the specialist will take on the full management of the IBD patient, but the specialist isn't responsible for the preventative elements or day-to-day management of IBD, nor the first response to an acute episode. The GP plays a central role in the patient's holistic care needs including managing any comorbidity.

To ensure comprehensive and continuous care, a multidisciplinary, chronic disease-focused, team-based approach is required (Figure 12). GPs believe the core teams members should be:

- patients, carer and family
- GP and specialist (working in collaboration for the benefit of the patient)
- dietician
- psychologist.

Extended IBD team members could include:

- other allied health, noting that it is often *'difficult to access allied health clinicians who have an insight into IBD'* in the community setting and particularly difficult to access incontinence care
- other specialists (e.g. obstetricians, rheumatologists, oncologists etc.)
- peer support groups and other support services.

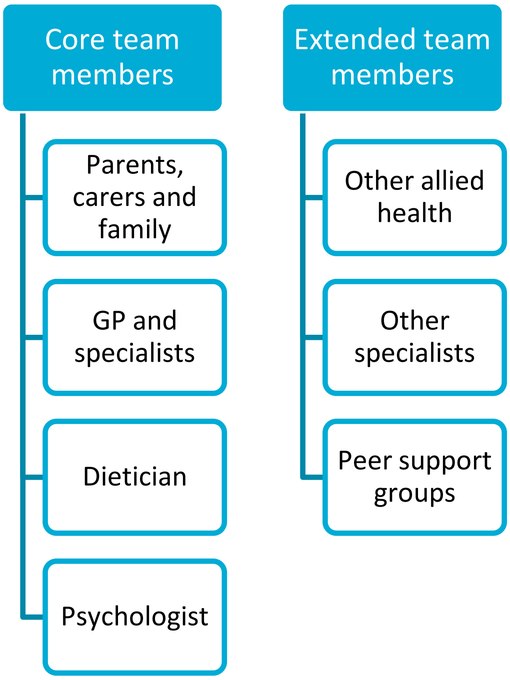


Figure 12: IBD multidisciplinary team-based care suggested by GPs.
Source: Developed by AGPAL on behalf of CCA.

Participants felt that the person-centred care team may be more comprehensive for '*complicated patients who have extra manifestations outside their gastroenterological problems or they have eye problems or they have joint problems and they will need to [engage with the] pathologist, ophthalmologist and rheumatologist.'*

Interestingly, GPs recognised that once patients are in the system, public patients may have better access to allied health services (either through the MBS or the public hospital system) than private patients, who may not have extras cover or who may struggle to afford the gap payment for such services.

Few GPs reported that they routinely utilise a GPMP for IBD patients, although they recognise that patients often have multimorbidity and psychosocial needs and require access to allied health and educators in addition to the GP and GEs. They pointed out the limitations of the GPMP: '*The GPMP only provides access to five allied health sessions in the year…and that covers all comorbidities'.*

No GP was using or party to a shared care plan and none had considered developing a sick day action plan with a patient.

When it comes to the management of patients, GPs typically take the lead from advice from:

- GEs during advice-seeking calls or in summary discharge or other correspondence
- patients who give feedback on advice provided to them by their GEs.

GPs did, however, recognise the challenges this presents:

- wait times for access to GEs (either a new referral or follow-up appointment) are long and they need to understand how to manage patients in the intervening period:
    - *'I need to know I'm not doing any harm…whether it's appropriate to prescribe steroids… and for how long, when to reduce/take off steroids etc.'*
    - *'People can access GPs quickly but they can't access their specialist and they become very unwell, and we actually may be able to give them relief of their symptoms*.'

All GPs agreed the following would aide communication between patients and health professionals, clarify goals of care, and establish a co-designed and agreed treatment plan that should hopefully enhance health literacy and enable greater adherence to optimal care:

- **cycle of care** – setting out patient requirements, timescales and responsibilities etc., potentially supported by a checklist and MBS cheat sheet
- **shared care plan** – setting out patient goals for health and wellbeing, roles and responsibilities within an agreed cycle of care, self-management and circle of support etc.
- **sick day action plan** – clarifying red flags, actions to take and who to reach out to at the onset of flare-ups.

5.1.3. Health literacy

5.1.3.1. Preliminary survey results on patient health literacy

A component of the preliminary survey was patient health literacy. Participants' responses to improving patient/families' and carers' health literacy and awareness included:

- continuous patient, community and support group education:
    - *'IBD can be a big burden on the patient and their families. They require a good understanding of the situation and possible outcomes of the condition. This requires constant education and professional support groups.'*
- specific formats:
    - YouTube videos
    - information to patients via flow charts, factsheets, leaflets in waiting room in an easy and simple format

        - *'Plain language summaries of key facts. Consider distributing hard-copies to relevant services…'*
    - a consumer phone app
    - IBD association and website
        - *'…through a central IBD association and website'*
- links to information sheets through GP software to improve GP-patient interactions:
    - *'Availability on GP software to email to patients, handouts to give out to patients.'*
    - *'Online site to refer to. PDF documents from practice software to be printed out or sent to patient by email.'*

The preliminary survey asked GP participants to provide factors for improving patient health literacy and awareness of IBD guidelines. The following themes emerged:

- delivery of information – via workshops, courses and storytelling:
    - *'Storytelling and making it real and interesting.'*
- easy access and understanding – free resources, easy to access and easy to understand:
    - *'Avoiding overwhelming amounts of information, explaining that circumstances differ for all patients so they are only a guideline.'*
- enhancing GP knowledge – rather than the primary role of the GP to only refer IBD patients to specialists, will not only build a good connection between GPs and patients but will provide continuous education of the GP alongside patients:
    - *'Building a good connection with their GP and continuous education of the GPs alongside patients.'*
    - *'Technically, this can be achieved by enhancing the knowledge of GPs in this regard instead of being a referral machine.'*
- language appropriate – guidelines in different languages and in lay terms, in a simple format and with a stepwise approach:
    - *'Vastly varying levels of health literacy among different patient groups. Consider translating resources to improve access to CALD groups.'*
- stakeholder coherence – agreement by various stakeholders.

5.1.3.2. Focus group/semi-structured interviews

Building on the results around barriers to and suggestions for improving patient IBD health literacy, GPs were prompted to further explore this topic and consider the currently available materials and tools and the factors to consider when developing health literacy materials.

Patient health literacy

GPs affirmed that they support patient interaction with clinical guidelines but pointed out that patients often have '*low levels of expectations'* and low levels of activation. GPs said that patients seldom want to review protocols or guidelines, and since the guidelines are written for clinicians they are often complex and confusing for most patients (and this may lead to disengagement).

GPs reported that the most effective patient information should cover:

- the condition and its trajectory

- symptoms
- '*when to seek advice*', noting that patients may have '*tried different remedies [or] different things*'
- preventative health and why it's important (e.g. screening regime, immunisation)
- the importance of a healthy diet and nutrition:
  - '*Patients want information on diet*.'
- red flags, such as:
  - '*side effects of medication*'
  - *'complications'*
  - triggers for flare-ups
  - '*changes in their condition*'
- advocacy, enablement and self-management:
  - how to engage in shared decision-making and develop care goals and care plans
  - what a good day looks like and how to live with the condition
  - *'What you should be doing to look after yourself in general'*
  - what to do on a 'sick day' and who to reach out to (e.g. use a sick day action plan)
  - the efficacy of alternative medicines:
    - *'Patients want more information on…homeopathy.'*
- other important elements such as :
  - maintaining an enduring relationship with the clinical team and at minimum the core team (GP and GE)
  - adhering to the treatment plan and building self-management capability and confidence
- establishing consumer networks and supports including areas such as:
  - consumer rights and expectations
  - peer supports and benefits of joining self-management education groups:
    - *'To be able to link people up with support groups…so to have information about support groups at hand for patients.'*
    - *'I've had the full works myself and being able to engage with the support group, it was incredibly powerful…particularly when I had to consider a pouch surgery (protocolectomy). It was just amazing to be able to get online and read other people's stories.'*
    - *'I know from personal experience of using a sort of specialist nurse – chronic disease type nurse – they're really quite informative because from my experience they also run self-management groups for consumers as well.'* [It was noted that the IBD specialist nurse at tertiary centres may run self-management education programs]
- eligibility for community-based services (Note: While not expressed, this reflects the concept of social prescribing)

Note: A few GPs where not aware of CCA or the resources and supports available to patients.

Health literacy materials and tools

GPs recommended some ways to provide health literacy materials such as:

- in downloadable and printable form
- as *'links to videos or links to other media'*
- via patient education and self-help groups.

GPs mentioned some tools and resources for sourcing education materials for patients:

- **Crohn's & Colitis Australia** (CCA) – provides information on IBD to patients. Website content often showcases downloadable materials and networks. Patients may be encouraged to join peer support groups, but GPs recognise this is a personal choice for each patient and membership comes at a cost. Also, services may not be accessible to rural and remote communities or transient populations.
- **Patient.co.uk** – this site has freely available condition leaflets for patients (written by and for patients) and doctors' pages known as 'Professional Plus'. GPs feel the patient leaflets are very informative and often print them off and hand them to patients.
- **Practice software** (e.g. Medicare Director) has some patient handouts:
  - some GPs do not trust this content and as such are reluctant to use the resources because they *'[contain] too much drug promotion'* and '*don't have enough independence'.*
  - one GP mentioned that it would be helpful if their CIS had plug-ins to a central repository of resources or a consumer-focused information tool.

One GP mentioned: *'If we're going to do that [increase patient awareness] we're going to have to increase GP knowledge of the guidelines'*, thus reinforcing the need for GP awareness, education and training.

Another GP mentioned: *'Having clear, simple information to give to patients is excellent... To have a centralised database where you could click on the title of the topic and spit out a PDF, it would be fantastic.'*

GoShare Healthcare

While participants did not mention this tool during the review, the review team came across GoShare Healthcare (Healthily).

GoShare is an intuitive online tool that makes it easier for clinicians and patient educators to send appropriate and timely educational resources to consumers (Figure 13).

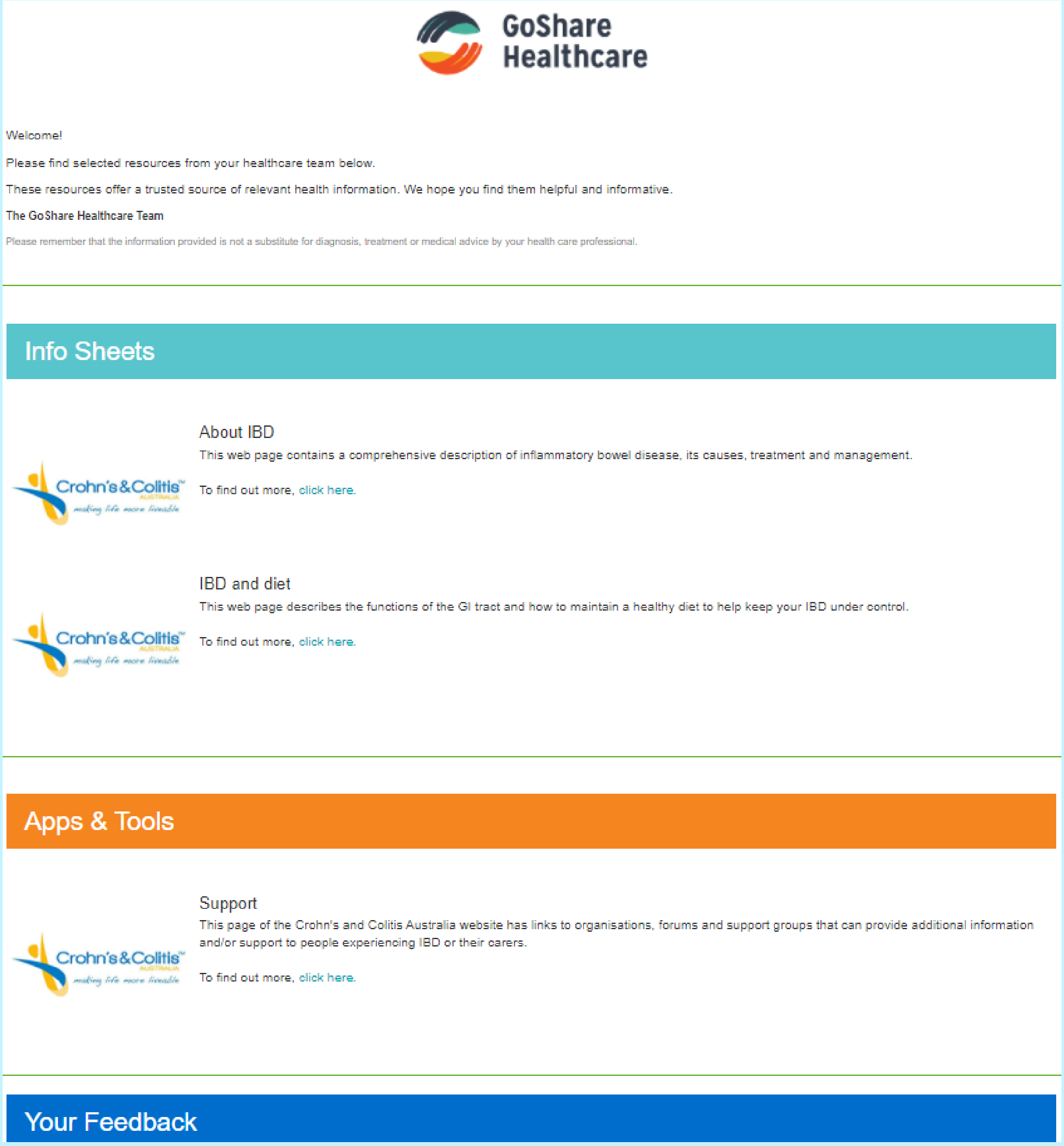
This function allows patients to engage with the materials in their own time, with postings scheduled before or after visits to either inform consultations or to reinforce education and self-management post consultations, thus building health literacy.

GoShare is currently integrated with CAT4 (by Pen CS), with the Medical Director side bar, and will be integrated with Best Practice in the next few months.

Clinicians and health educators can select from a range of resources appropriate to patient need at any given time and push this information via SMS or email to patients accordingly. (Note: The cover email or SMS is tailored to each practice.)

Presently the Healthily site has 20 IBD fact sheets and 10 tools or resources.

The review team is also aware that other similar tools are in development.



Welcome!

Please find selected resources from your healthcare team below.

These resources offer a trusted source of relevant health information. We hope you find them helpful and informative.

The GoShare Healthcare Team

Please remember that the information provided is not a substitute for diagnosis, treatment or medical advice by your health care professional.

Info Sheets

About IBD

This web page contains a comprehensive description of inflammatory bowel disease, its causes, treatment and management.

To find out more, click here.

IBD and diet

This web page describes the functions of the GI tract and how to maintain a healthy diet to help keep your IBD under control.

To find out more, click here.

Apps & Tools

Support

This page of the Crohn's and Colitis Australia website has links to organisations, forums and support groups that can provide additional information and/or support to people experiencing IBD or their carers.

To find out more, click here.

Your Feedback

Figure 13: Illustration – Healthily IBD patient email.

Source: Used by AGPAL with permission by GoShare Healthcare

Developing health literacy materials

GPs said health literacy materials should be:

- tailored to both patient literacy and activation levels
- built on intrinsic motivations
- *'interesting and engaging and then people would be more likely to follow your advice'*
- delivered through age-appropriate modes.

Examples of age-appropriate delivery modes are:

- Using humour and social media platforms to reach youth. GPs highlighted on several occasions the issue of youth not complying with clinical regimes, yet we know humour is a big factor in social marketing for this age group. Youth predominantly use social networking platforms and video content to access information and communicate with peers so it makes sense to use these methods.
- *'I don't have the GESA website in front of me but maybe an information for patients section [would be helpful] because I'm sure that most of the patients that are very highly health literate will be looking at the guidelines as well. Maybe having a[n] information for patients section will help explain some of those things that might be difficult for someone without medical knowledge to understand.'*

> *'There's a young woman on one of the social medica platforms – I think it's Facebook – who has quite severe IBD…who [has] had colectomies and has a colostomy, and all the rest of it. She has a whole lot of inspirational videos about how to get on with your life and how to do things, and how you don't have to be stopped by anything and I know that some of my younger patients have found those very helpful.'*

In addition, GPs several times raised the **need for culturally appropriate patient information in multiple languages**:

- *'I work in an Aboriginal medical service, and yeah, having culturally appropriate info is really important. For asthma there are the sort of [materials that] have been developed with the Aboriginal community to have. I guess more targeted things that kind of present messages in a way that is more likely to be received or understood.'*

One GP mentioned they had worked in remote Northern Territory and had not experienced any patients with IBD type symptoms. Another GP mentioned that while they were not aware of the prevalence of IBD among Aboriginal and Torres Strait Islander people they felt '*it would probably be similar to the wider population'.*

- *'Patient information needs to be simple and direct…and in appropriate languages.'*
- *'I work with a very low socioeconomic patient group with lots of people who don't speak English and finding translatable resources is a daily challenge. If by any miracle, we could come up with resources in other languages – and not just Vietnamese, that would be tops!'*

Some GPs mentioned that they don’t provide patient information or guidance on how to access additional information and resources but rather simply *‘sit with the patient and see them more frequently and explain* [the condition] *to them’.*

On the whole, the GPs recognised they need to treat each patient as an individual and tailor communication accordingly, but none knew about the Patient Activation Measure®:

- *‘You have to see their age group…the older people, the younger people and you have to really differentiate.’*

GPs mentioned that patients don’t typically provide information on IBD but, when they do, the GPs often find it challenging to validate information provided and manage the expectations of patients who:

- visit ‘*Dr Google’* or watch news/topical programs on the TV:
    - *‘Patients will come with something that they’ve found on Google or something somewhere and they’ll want to know whether this is good or not.’*
- bring unsubstantiated papers on alternatives to medication that have not been peer reviewed and have no or limited scientific base.

These patients are often generalised as *‘the worried well’*, with GPs noting:

- *‘Sick patients are open to GP information [and guidance].’*
- *‘Sick patients often educate GPs in IBD’* utilising information obtained from the GE.

As mentioned, the GPs felt that decision support tools (e.g. decision trees, flow charts and algorithms), cycles of care, shared care plans and sick day action plans are lacking but would be welcomed. GPs felt that these tools, together with summary information sheets that support options appraisal and decision-making at each stage of the patient journey, would be extremely useful to patients and GPs:

- ‘*We could give them a flow chart and then they can work through options and potential next steps.’*
- *‘I often find flow charts are helpful there, especially helpful to explain to patients, sometimes. If you actually can just show them the flowchart and explain why you’re making the decision you’re making.’*

A tool like a decision tree/flow chart would help to inform and track the individual patient journey (including stoppages when things don’t work to plan, and which step to return to when considering an alternative approach).

5.1.4. CPD, education and training

5.1.4.1. Preliminary survey

The preliminary survey asked participants to **clarify their CPD needs and priorities for IBD management.** These three major themes emerged:

- **knowledge** – updates on new developments in guidelines and management; information about diagnosis, diet, surveillance needs, management, treatment and medications; the differences between IBD and IBS and the different presentations; and what to do for management when referrals to specialists are lengthy:
    - *‘I think it is very important to differentiate between IBD & IBS.’*

   - *'IBD is a complex syndrome. It can affect different organs and manifest itself in different ways. Therefore, GPs should be considering IBD as a differential diagnosis in different presentations. Furthermore, GPs are well placed to diagnose IBD in time.'*
   - *'I will need to be able to manage IBD more myself as waiting times to see gastro is getting longer.'*
- **tools and referrals,** including highlights, symptom red flags and a GP management plan:
   - *'It would help to clarify what are the symptoms that would raise red flags for IBD – and when to refer to specialist in a patient with known IBD.'*
- **training** – explanations of GP roles in IBD management; opportunities to manage CD and UC in the community; simple annual updates; and articles in AJGP and AusDoc with CPD points:
   - *'During training, there was minimal opportunity to manage colitis and Crohn's patients in the community. I am hoping to gain more knowledge by participating in this focus group.'*

GPs also established that they prefer CPD to be delivered as face-to-face workshops followed by online webinars/workshops and eLearning modules and resources (Figure 14). GPs also suggested multi-choice questions with explanations of why an answer is incorrect/correct, educational visits and having good quality resources to access when needed.

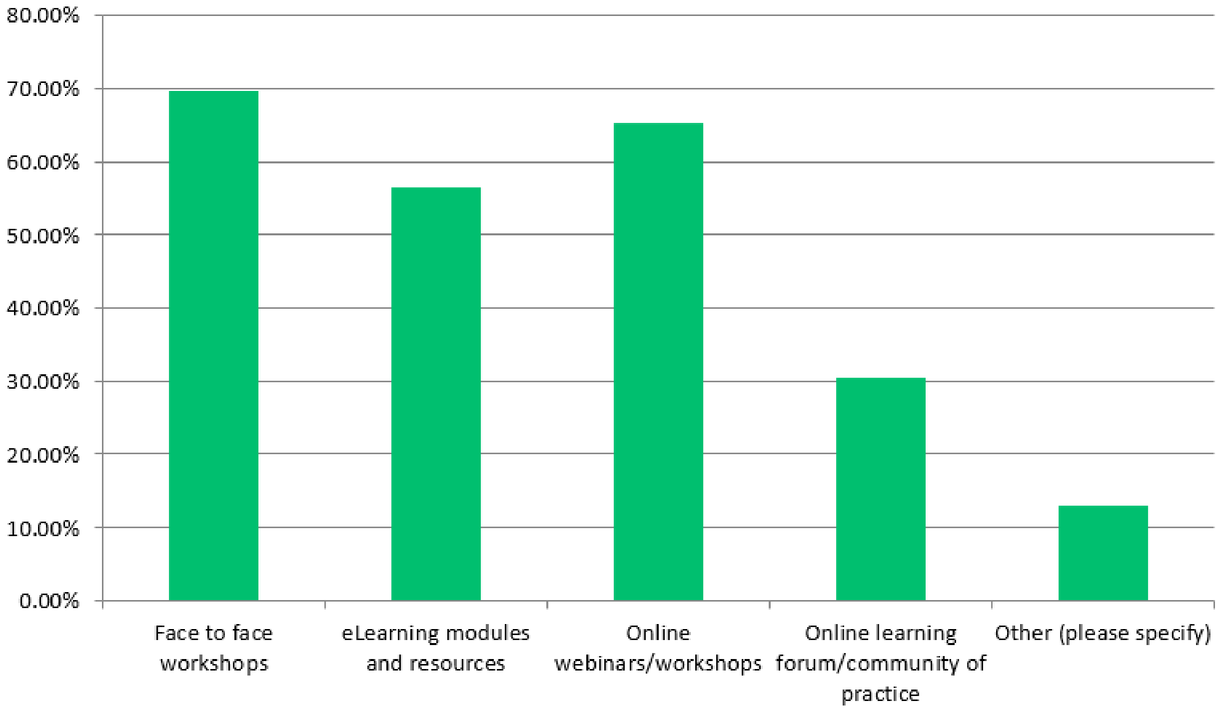


Figure 14: CPD mode of delivery preferences.
Source: Developed by AGPAL on behalf of CCA.

5.1.4.2. Focus group/semi-structured interviews

Following on from the preliminary survey, the focus groups and semi-structured interviews further explored CPD. GPs commented on the available CPD, the topics that should be included in a CPD program, and how they should be delivered.

Current IBD CPD for GPs

> *'Help us with the emergency, acute presentations, maintenance therapy, prevention therapy and complications therapy.'*

The GPs recognise the increasing prevalence of IBD within the community and the need for awareness raising, as well as education and training on the diagnosis and management of IBD:

- *'There's no IBD training being done [that I'm aware of]!'*
- *'It is a complex and challenging condition.'*

However, given the '*rarity'* of the condition in general practice and low patient numbers, GPs questioned whether they would routinely attend face-to-face education and training unless they had a significant number of patients or it happened to be advertised and held when they had an identified and explicit need to upskill to better address patient need:

- *'This is considered a rare condition.'*
- *'Everything is online if you want to find it but we need [to have a] need for it but [it will be] competing with other GP needs and time.'*
- *'We need to balance the number of consultations versus the need for knowledge on a topic.'*

One GP mentioned that any promotional material for GP education on the topic of IBD would need to highlight their current deficits in knowledge and clinical management before they would consider the need for training. While provocative, this statement highlights the need for a 'hook' to promote the need for engagement (i.e. clarifying 'why' they need to know).

Preferences for CPD training

When asked to consider their experience of a good CPD program, GPs affirmed preferences for a mixed mode of delivery encompassing both on-demand and scheduled training supported by regular updates on emerging research. This could cover:

- on-demand (asynchronous) bite size (no more than one hour) pre-recorded educational training resources such as:
    - e-modules with the ability to '*easily navigate through [content] and learn from them'*:
        - *'I'm happy with online teaching as it saves travel time.'*
        - [It should] *'contain the opportunity to ask questions'.*
        - *'They can be supported by resources and activities.'*
    - recorded videos, talks, webinars, updates etc.
    - podcasts covering, for example, clinical guidelines, patient stories or updates
    - reference materials, articles and papers, including an understanding of research projects in hand and research findings.

The benefit of this approach is that GPs could upskill in their own time at their own pace, dipping in and out of materials as required while navigating the patient journey.

GPs also suggested scheduled (synchronous) activities including:

- online webinars/workshops (no more than an hour and a half), with scope to answer questions and undertake polls to test knowledge and *'ask any questions'* (*'There should be a question time'*) and where *'resources [are sent] through email or electronic media'* before or after the workshop to reinforce learnings
- face-to-face workshops (up to three hours on a Saturday morning) and local clinical network meetings and educational workshops (evenings, with dinner provided):
    - *'Face-to-face usually…a workshop…[on] a weekend, if you're going to involve a dietician, psychologist and gastroenterologist…people will keep talking to each other.'.*

The benefit of this approach is that it would facilitate knowledge transfer through dialogue. *'You might read something, but you don 't comprehend the importance of that. But when you go to a workshop with, say, a specialist [speaker and] they point it out, then you realise the…importance of that fact.'*

In one focus group, the review team asked the GPs whether they would welcome an online chat room, moderated by leading clinicians, in which they could pose questions and receive responses that could be shared across the community of practice, and over time also have a set of frequently asked questions (FAQs). Interestingly, the response was negative. GPs advised they don't have the capacity to engage at this level and that such interaction needed to be as close to real-time as possible, in which case they would simply reach out to a colleague or their local GE service for advice and guidance.

The suggested mix method approach allows GPs to develop their own personalised CPD and growth program in which they could learn and then test or expand knowledge in their preferred mode:

- *'I prefer starting with online learning programs. And after that…face-to-face workshops.'*
- *'I prefer live face-to-face education over paper exercises with summaries.'*
- *'[We need to ensure a] baseline level of knowledge from training…it's up to the GP to increase knowledge and upskill…[although] recognising that IBD prevalence is low.'*
- *'I think a package. If you've done one meeting face-to-face, and one meeting online or two meetings online plus pre-questionnaire, pre-clinical audit and post-clinical audit to get the 40 points would be excellent. I think 40 points usually appeals to GPs.'*

Not all GPs agreed that clinical audits are helpful or that GP CPD points are important:

- *'130 points in a year – it's not hard to get.'*
- *'Points don't attract me.'*

CPD content

GPs suggested the following content for education and training (Figure 15):

- **awareness and early identification** of the condition and factors to consider when querying whether someone has IBD:
    - *'...the symptoms and signs to look for to help diagnose IBD and differentiate with IBS.'*
    - [differentiating between IBS and IBD]: *'What's the difference and how do you distinguish?'*
- **patient stories and journeys** – lived experience of the patient journey; appropriate interventions and learnings along the way; how to engage patients ('*How to ensure they don't fall off the radar*'); how to activate patients and enhance self-management capabilities and supports; and how to establish a long-term enduring trust-based healing relationship with patients (a *'long term structure'*)
- **screening and diagnosis** – screening including faecal calprotein (FCP) testing; how to access and/or alternatives for when a patient can't afford to pay (Note: this isn't covered by MBS); and INF Gold > Latent TB testing – when and how to undertake; diagnosis including interpreting results and differentiating between results (e.g. clinical indicators such as FCP may be elevated by other conditions)
- **referrals and triage** – the right time to refer to a GE, the indicators, what constitutes a quality referral, the clinical history required, the tests that should be undertaken and the results required to inform the referral, how patients are risk stratified/triaged, the target wait times, by category of patient
- **shared care planning** and multi-disciplinary working – the optimal multidisciplinary team (by patient scenarios and including examples of optimal care) including the role of allied health and '*when to refer to allied health'* including, for example, dietician, psychologist, physiotherapist/exercise physiologist, skin specialist (cysts), incontinence nurse, and pharmacists, plus other specialists including rheumatologist for the immunosuppressed, oncologist, surgeon, geriatrician, obstetrician, and psychiatrists etc.; clinical leadership, teamwork and collaboration (what makes it work); and tools and resources, including how to link and leverage the MBS, PBs and other source funding
- **preventive factors** and strategies – including SNAP; immunisation and vaccination regime; diet; exercise; anxiety, depression and stress management; wellbeing; employment; and social connections and networks
- **management** –
    - IBD management before first GE consultation and formalised diagnosis
    - IBD maintenance regimes (post diagnosis)
    - management of an acute flare (pre and post diagnosis) and emergency situations:
        - '*case studies illustrating common and normal symptoms of an attack'*

        - *'acute management and anything dangerous…like is there anything dangerous we can do? Or rather we want to avoid doing… [such as] leaving it for five days is dangerous or giving them Methotrexate is dangerous?''* (Note: This introduces the concept of patient safety and quality)

    - management of comorbidity (pre and post diagnosis), for example:

        - *‘other stuff that’s related to immunosuppression’*
        - young people and eating disorders, where a multidisciplinary team approach encompassing dietician/nutritionist and psychologist with an interest would assist

- **medications**, medication management, contraindications and side effects:
    - *‘when to change medication’*
    - *‘I’ve rarely had to start people on Prednisone and I’m a bit, I’m a bit scared to start people on steroids.’*

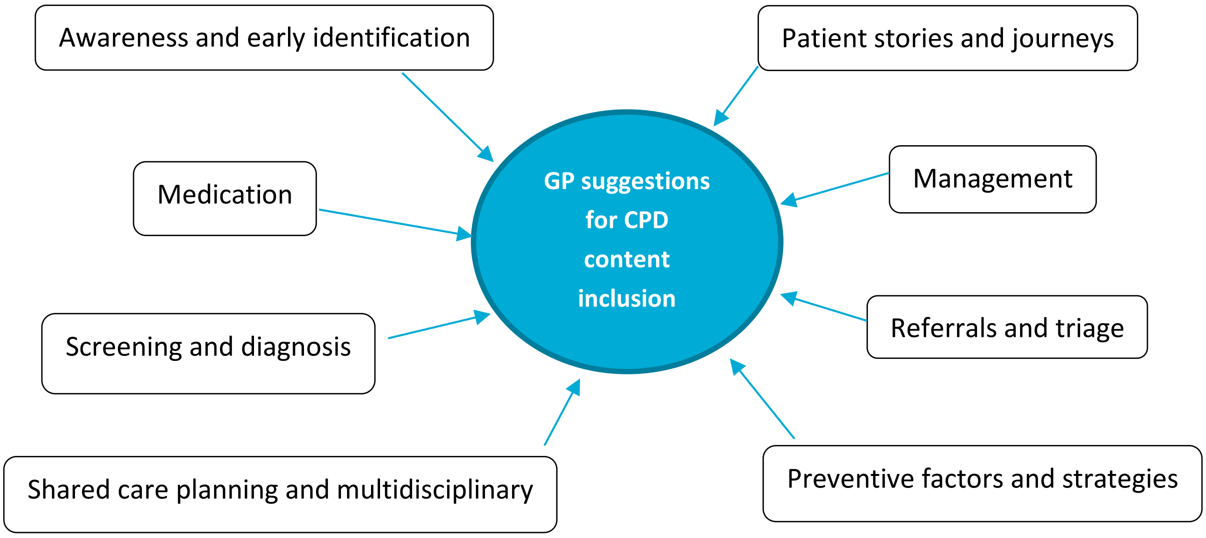
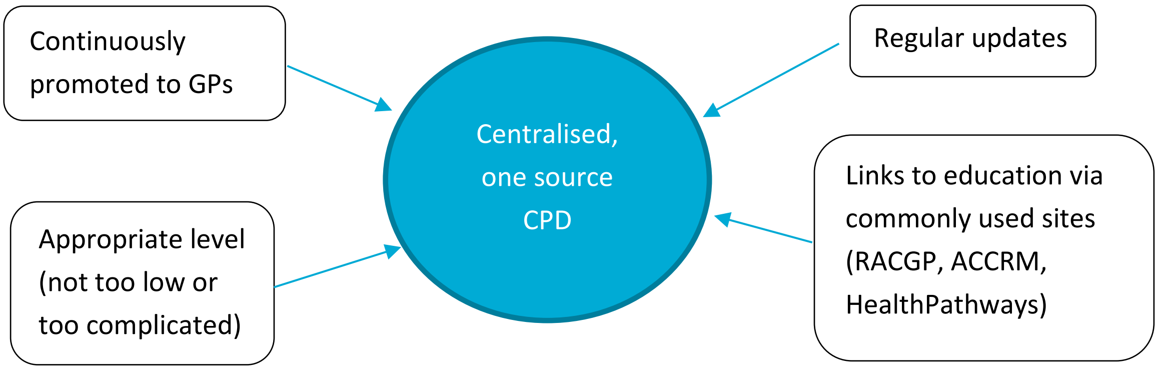


Figure 15: GP suggestions for CPD content inclusion.
Source: Developed by AGPAL on behalf of CCA.

Participants noted how important it is that any CPD provide ‘one source’ that is available in a centralised place where it can be quickly and easily updated as appropriate (Figure 16). GPs would like to see this CPD:

- continuously promoted to GPs to ensure it is top of mind when education is necessary
- potentially ‘*hitch[ed] to a wagon’* to ensure it is easily accessible (e.g. links to the education platform provided via HealthPathways, RACGP, ACCRM and GESA sites, publications/resources and other information/education providers such as GP Hot Topics)
- pitched at the appropriate level (i.e. not too low), noting there were mixed views on whether combined GP/GE training is appropriate:
    - *‘Generalist GEs may be interested in the training but again it would need to ensure that this was pitched appropriately for them also’*
    - *‘I guess the level of information would be targeted just right to our [GP] level and therefore not considered suitable for GEs.’*
    - *‘There may be some things in common between GPs and generalist GEs.’*

- **supported by a repository of regular updates** (online, paper and publications, blogs/recorded webinars) on advances in IBD management to extend knowledge (e.g. new medications, research findings etc.) and an archive of copies available through a central repository for easy access.



Continuously promoted to GPs

Regular updates

Centralised, one source CPD

Links to education via commonly used sites (RACGP, ACCRM, HealthPathways)

Appropriate level (not too low or too complicated)

Figure 16: GP CPD requirements.
Source: Developed by AGPAL on behalf of CCA.

Opportunities for collaboration in promoting and delivering IBD related education and training were raised and include:

- collaborating with NPS about updates on medications and medication management
- collaborating with GE registrars and hospital staff.

5.2. Gastroenterologists

5.2.1. Engagement, demographics and activity

A total of 21 GEs completed the preliminary survey: general GEs (30%) and GEs with a special interest in IBD (70%). Of these 21 GEs, eight worked in the public sector only, five worked in the private sector only, and eight worked in both the public and private sectors.

The number of years the GEs had spent in their profession ranged from one year to 20 years, with a mean of 9.15 years (±SD 6.86) with three, five and 20 years being the most common lengths of service.

Survey participants were geographically distributed as follows: 33.3% (n=5) from New South Wales and Victoria, 20% (n=3) from Queensland, and 13.3% (n=2) from Western Australia. Gender distributions were 46.7% male, 40% female and 13.3% preferred not to answer. Age of participants ranged from 30 to 56 years old, with an average of 37.9 years.

Participants identified that the total number of patients consulted per month ranged from 40 to 400. Of those, eight to 300 patients had IBD, five to 150 were classified with UC and three to 150 were classified with CD (Table 5).

	Total number of patients	Total number of patients with IBD	Total number of patients with UC	Total number of patients with CD
Min–max	40–400	8–300	5–150	3–150
Average (± SD)	150.8 (94.9)	59.3 (62.1)	30.8 (31.6)	29.55 (31.6)
Mode	200	20, 80	5, 30, 40	40

Table 5: Number of patients GEs see per month and the relative number of patients with IBD.
Source: Developed by AGPAL on behalf of CCA.

One GE reported that they see 400 patients each month, 300 of whom have IBD. This response was atypical and clearly skewed the results above. When removed from the equation, the results were:

- 137.7 (± SD 77.6) average number of patients
- 46.6 (± SD 29.2) patients with IBD
- 24.5 (± SD 16.32) patients with UC
- 23.2 (± SD 15.6) patients with CD.

Of the 21 survey participants, 14 GEs went on to participate in a focus group or one-on-one semi-structured interview.

5.2.2. Clinical guidelines: awareness, utilisation, preferences and useability

5.2.2.1. Preliminary survey

Results from the preliminary survey identified key themes on:

- access and utilisation of IBD guidelines
- preferences for IBD guideline use
- the general engagement preferences for using IBD guidelines.

Access and utilisation of IBD guidelines

Participants were asked how they access IBD guidelines: 52% access guidelines online, 17% via memberships/subscriptions, 13% through meetings, 9% via hospital resources and 9% via university libraries.

The top three resources or sources the GEs use to increase knowledge and inform clinical decisions are ECCO, journal articles and conferences (Table 6).

Resource/information	Response percentages
ECCO	22%
Journals	18%
Conferences	10%
Meetings	9%
UpToDate	4%
CPD	3%
DDW	3%
CCA	3%
CCUK	3%
GESA	3%
Local guidelines/meetings	3%
Webinar	3%
ACG	1%
AIBD	1%
Articles	1%
Medline	1%
CCC	1%
JJC	1%
Consensus guidelines	1%
EUGW	1%
NASPGHAN	1%
UEGW	1%

Table 6: Resources GEs use to increase knowledge and inform clinical decisions about the management of IBD.
Source: Developed by AGPAL on behalf of CCA.

The GEs most commonly used guidelines are ECCO (48%), GESA (13%) and AGA (10%) (Table 7).

	%	#
ECCO	48	15
GESA	13	4
AGA	10	3
Australian UC guidelines	6	2
Hospital guidelines	6	2
Australian IBD standards	3	1
BSG	3	1
CCUK	3	1
Department guidelines	3	1
NASPGHAN	3	1

Table 7: IBD clinical guidelines that GEs use.
Source: Developed by AGPAL on behalf of CCA.

When presented with a list of 32 online IBD guidelines, factsheets and protocols, participants were asked to identify their awareness and utilisation of each (Figure 17; Supplementary Table 1).

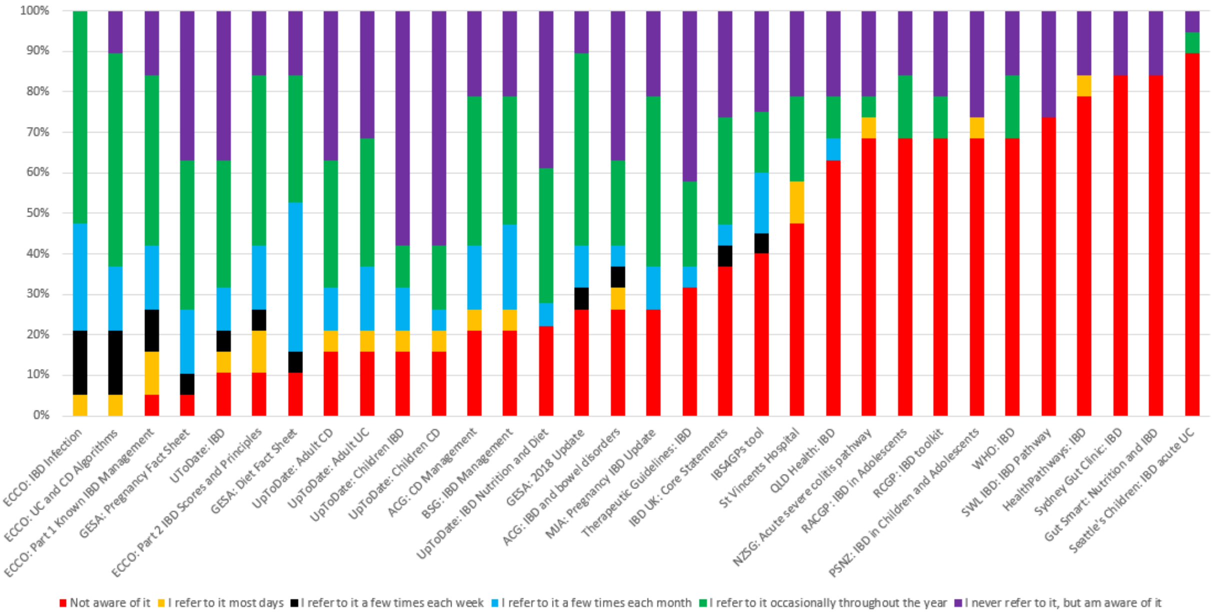


Figure 17: Awareness and utilisation of IBD guidelines.
Source: Developed by AGPAL on behalf of CCA.

The preliminary survey asked how often participants sought advice from other specialists and 5.3% responded ‘always’, 26.3% said ‘usually’, 57.9% reported ‘sometimes’ and 10.5% responded ‘rarely’ (Figure 18). No participant said they never sought other specialist advice when needed.

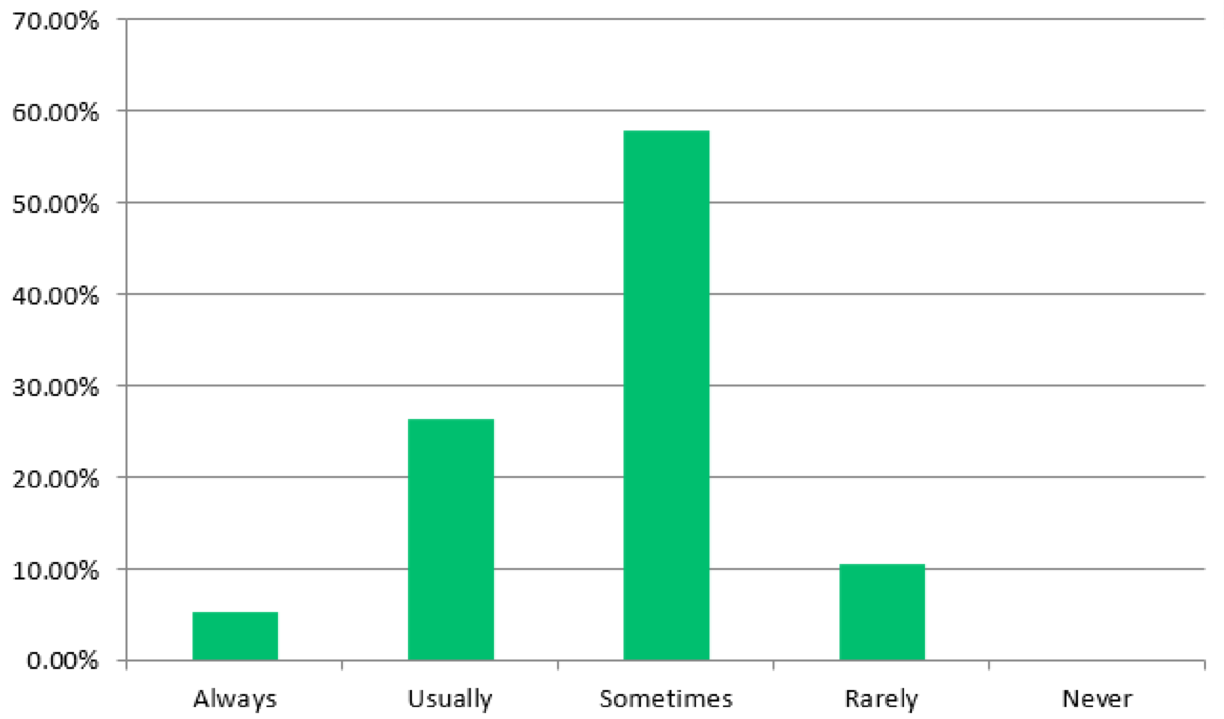


Figure 18: Frequency with which GEs seek additional specialist advice.
Source: Developed by AGPAL on behalf of CCA.

Participants also specified the frequency of allied health engagement, indicating that pharmacists and dieticians were typically involved in the care team and they accessed others according to patient need (Table 8).

Allied health	**Always**	**Usually**	**Sometimes**	**Rarely**	**Never**
Pharmacist	5.3%	15.8%	15.8%	36.8%	26.3%
Dietician	10.53%	73.7%	15.8%	0%	0%
Physiotherapist	0%	0%	36.8%	42.1%	21.1%
Exercise physiologist	0%	0%	26.3%	42.1%	31.6%
Psychologist	0%	21.1%	68.4%	10.5%	0%
Psychiatrist	0%	5.6%	33.3%	50%	11.1%

Table 8: Frequency with which GEs refer to allied health.
Source: Developed by AGPAL on behalf of CCA.

In the preliminary survey, GEs' responses showed three major themes around how to increase awareness of IBD guidelines:

- **format** – having a single portal and list of guidelines, reducing the number of guidelines available, creating a phone app, using both digital and paper format and making access easy and free relevant to target audiences:
    - *'There are multiple guidelines in various places that make them difficult to find – a single portal may be helpful. Some are created and distributed by GESA, but this survey reminds me*

that I have seen them a while ago but have not used them since. Guidelines are often difficult to find quickly on various society webpages, unless you know which links to use.'

- **knowledge** – increasing the education activities during medical training and increasing the number of courses and conferences for IBD:
    - *'Through educational activities at all levels starting from medical schools, internet links when searches are done for IBD related topics, incorporation in publications, through informed patients.'*
- **promotion** – using local meetings, reminder emails, newsletters, GESA membership; creating an 'awareness week'; and providing links to guidelines in publications.

Guideline preferences

The GEs in the preliminary survey prefer these three IBD guidelines:

- UC and CD algorithms by ECCO
- ECCO–ESGAR diagnosis, monitoring of known IBD and detection
- equally rated ECCO-ESGAR IBD scores and GESA's pregnancy fact sheet (Figure 19).

When asked why they prefer these guidelines, the following themes emerged:

- **content** – comprehensive, reliable and suitable to Australia. GEs have a general confidence in these guidelines and an understanding that they are up to date. They also reflect global strategies and provide useful information generally but also for IBD specialists
- **use** – easy to find, easy to access and user friendly
- **other** – used in teaching medical student and junior medical doctors; often given to patients and GPs looking after patients; seen at ECCO conferences.

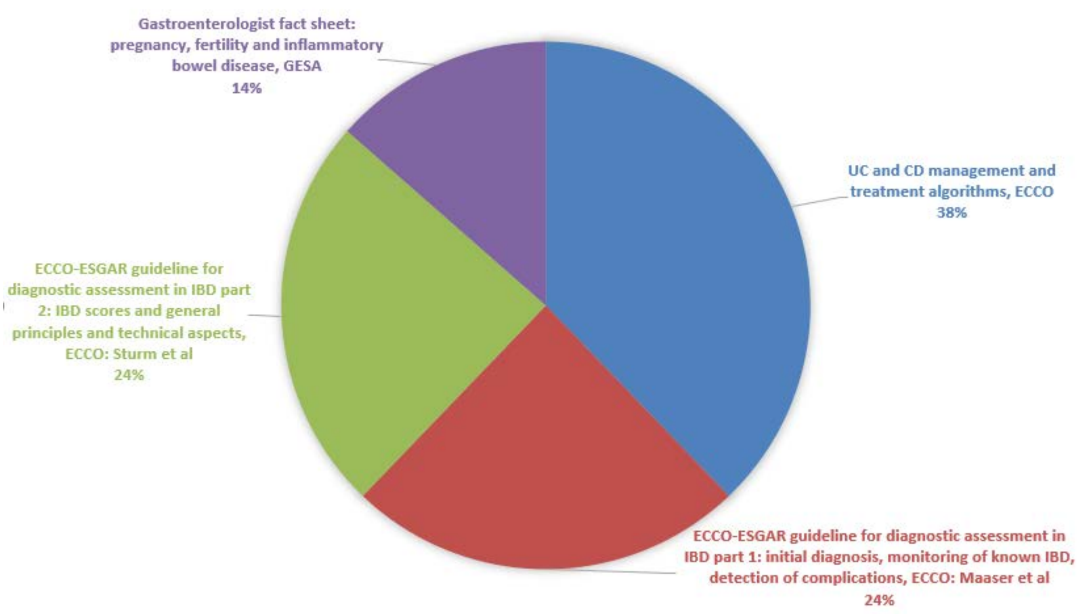


Figure 19: GEs' top three preferred guidelines.
Source: Developed by AGPAL on behalf of CCA.

Useability of IBD guidelines

The preliminary survey asked GEs how they would generally access IBD guidelines. Access via international professional body websites was the most common response, followed by access via Australian professional body websites (Figure 20). The third most common response was 'other', such as UpToDate, Google search, PubMed and journals via online libraries.

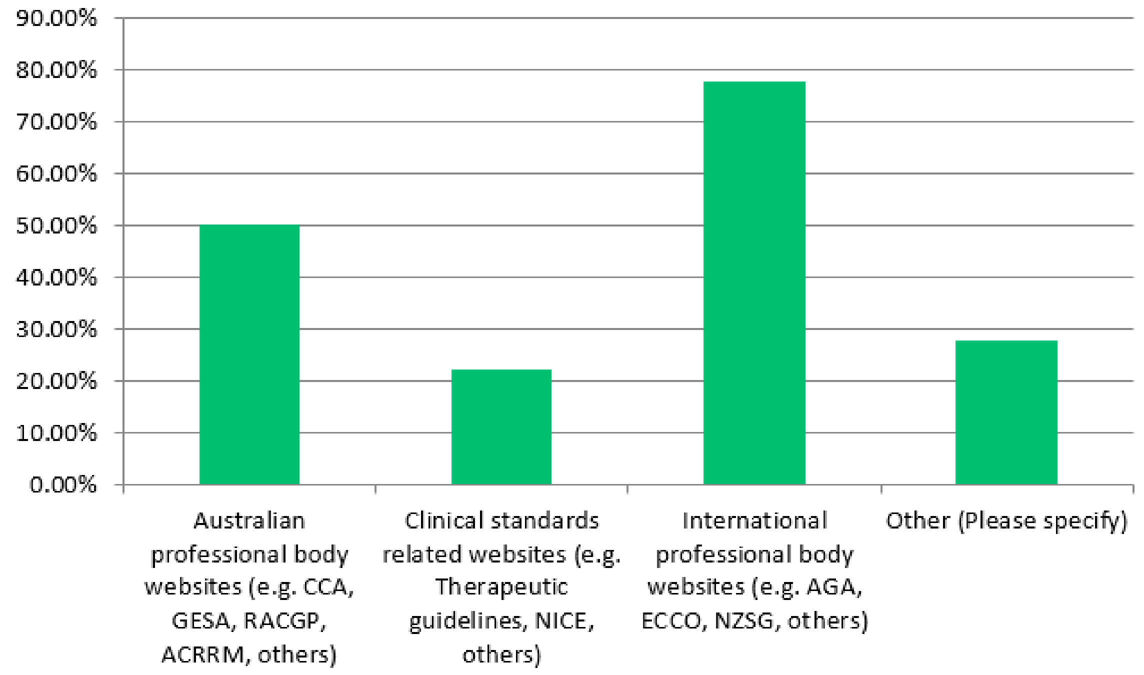


Figure 20: How GEs access IBD guidelines.
Source: Developed by AGPAL on behalf of CCA.

When asked what tools they use to access IBD guidelines, GEs most commonly said Google Scholar/Google search (Figure 21).

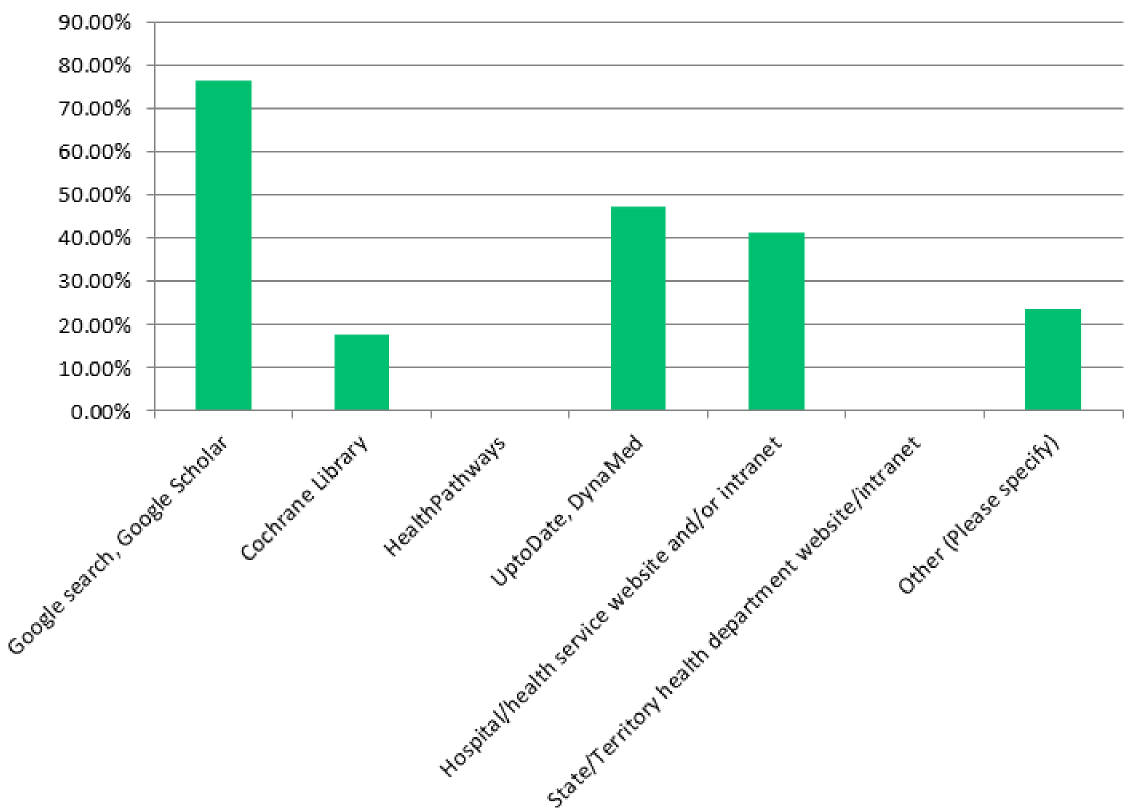


Figure 21: The online tools GEs use to access IBD guidelines.
Source: Developed by AGPAL on behalf of CCA.

Common responses to what participants like about the accessibility of these guidelines were that they are easy to find, reliable, concise, accessible, comprehensive and have a clear format (Table 9).

However, participants wish to improve various aspects (Table 9):

- having an Australian set of guidelines
- generally increasing knowledge of existing guidelines
- gaining easier access to guidelines
- accessing summaries and simple versions
- having a central and publicly accessible website containing all guidelines.

Participants suggested ways to increase awareness, access and utilisation of IBD guidelines (Table 9):

- creating a phone app
- making guidelines easy to find/search and free
- having a comparison of all available guidelines
- improving GP knowledge and utilisation of guidelines
- having a comprehensive list of guidelines available on GESA or a single portal for access
- promoting local IBD meetings for GPs
- incorporating guidelines into commonly read journals
- having patient-linked resources.

I like ...	**I wish ...**	**Suggestions**
Easy to find	Australian set of guidelines	Comparison of all guidelines available
Reliable	Easier access (phone app or digital)	Easy to find/search and free
Format: well set out, easy to follow, clear	Increase knowledge of existing guidelines	Improve GP knowledge and utilisation
Concise and evidence-based	A simple patient version	A list on GESA
Easy to access	Publicly accessible	Phone app
Comprehensive	Summary of all guidelines	Promote local IBD meetings for GPs
	Website with all guidelines	Single portal for access
		Incorporate into commonly read journals
		Patient linked resources

Table 9: GE preferences and suggestions for accessing IBD guidelines.
Source: Developed by AGPAL on behalf of CCA.

Overall, participants find the guidelines easy to use (Figure 22) as a result of their:

- **content** – clear and comprehensive, well set out, concise
- **format** – bolded summaries and good headings, clear tables, simple flow charts and algorithms
- **availability** – online and easy to search/navigate.

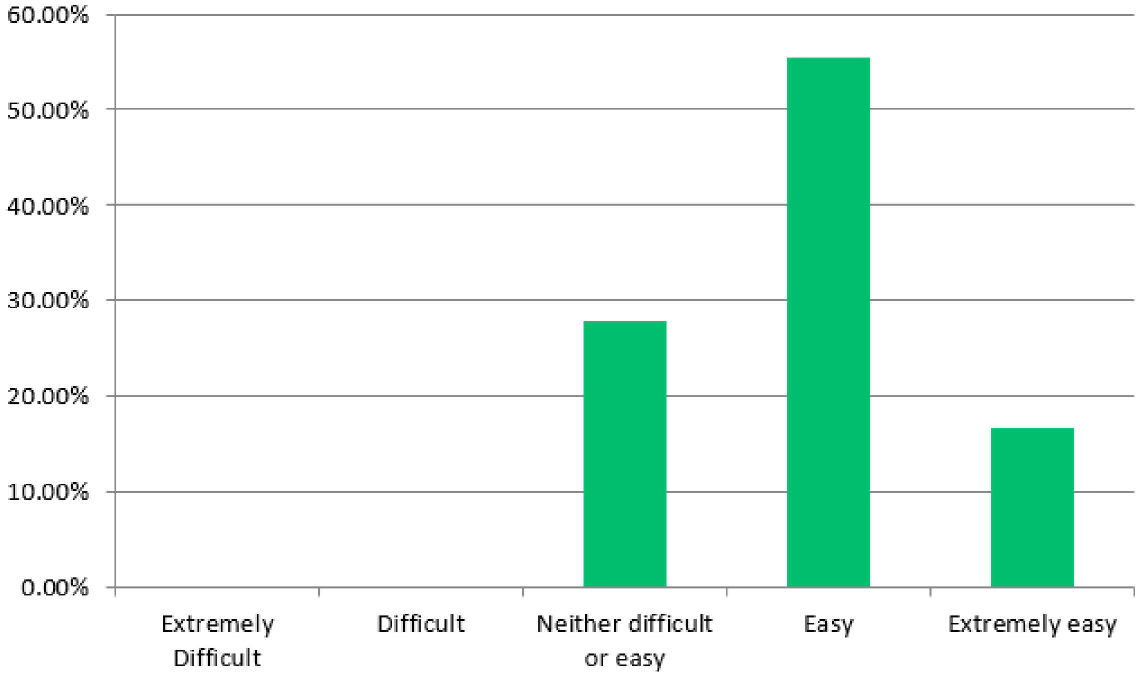


Figure 22: Ease of IBD guideline use according to GEs.
Source: Developed by AGPAL on behalf of CCA.

Suggestions from participants to improve useability of guidelines include:

- **availability** – easier access
- **content** – concise content relevant to most IBD situations but also with case studies of more complex cases (‘*More concise. Flow diagrams.’)*
- **format** – flow charts, summaries and algorithms that are interactive and a single source for GPs:
    - *‘More time to read them! Good summary pages/passages (ECCO and UpToDate do this well). Perhaps awareness e.g. professional events or webinars that take you through the pertinent and practical points of them? Could be run by IBD fellows/senior registrars for GPs?’*
    - ‘*Have key points summarising the literature. IBD management is becoming increasingly complex with new diagnostics, increasing medications and monitoring algorithms. Key points and figures (summarising these approaches) would be useful.’*
- **awareness** – define the GP role in IBD management and hold professional events.

The preliminary survey asked GEs to comment on factors to consider when using guidelines for education and training. They suggested:

- guidelines specific to specialists, GPs and patients
- frequent updates
- country-specific and familiar resources
- a phone app
- clarity on non-conventional treatments.

5.2.2.2. Focus group/semi-structured interviews

The trends and themes around clinical guidelines access, preferences and useability resulting from the preliminary survey prompted discussion questions for the focus group and semi-structured interviews. In particular, participants further discussed awareness and preferences, roles and management, suggestions for IBD guidelines, and multidisciplinary teams.

Awareness and preferences

Feedback from GEs (public and private) **corroborated survey results on the awareness and utilisation of IBD guidelines and preferences** for:

- **ECCO guidelines** – GEs considered these:
    - ‘*comprehensive and contemporary*’, covering ‘*a diverse range of information’* that addressed the ‘*majority of clinical questions’* and cohorts of patients, with information on research undertaken to fill any gaps
    - easy to access via a quick Google search or links saved on devices or computers
    - ‘*well structured’* and *‘easy to follow’* (e.g. *‘The flow diagram is easy to use.’)*
- **GESA guidelines**
- **journal articles** – provided useful information on advances in medications etc.

Feedback suggested ‘*there were so many guidelines that I wasn’t [we weren’t] aware of’*.

The GEs considered the ECCO guideline '*too comprehensive and complex*' for GPs and the GESA guidelines more appropriate. Conversely, GEs considered UpToDate *'not specific enough for GE management of IBD'* and possibly more appropriate for GPs.

Factors that typically inform a GE's choice of IBD guidelines include:

- training bias (i.e. content and handbooks used)
- connection with a tertiary centre and relationship with a particular specialist or team
- number of IBD type patients.

GEs reported that modern technology allows them to access multiple sites to address information needs and compare information, support clinical decision making or validate a particular course of action, but they said that '*a single website hosted by GESA for example*', housing links to guidelines, would be helpful.

Participants considered online versions of IBD guidelines easy to use.

A small number of generalist GEs were aware of HealthPathways, but no specialist GE was aware of it. No GEs utilised HealthPathways to access guidance on clinical guidelines, preferring instead to use the professional or peak body site (ECCO or GESA). GEs saw HealthPathways as being more beneficial to GPs since GEs have established referral pathways between secondary and tertiary services (public and private).

Participants mentioned in-house information platforms (e.g. St Alfred's intranet) but recognise that these often reflect professional or peak body guidelines and provide links to the respective websites, guidelines, tools and resources.

IBD management, roles and opportunities

IBD specialists clearly benefit from consistently using IBD related clinical guidelines, whereas **generalist GEs seem to find themselves in similar positions to GPs concerning the management of IBD patients**:

- *'If we go back to why are we looking at the guidelines both GPs and GEs, it's – we have a question. There's something we might not be sure about or we want to remind ourselves because we don't see this problem that often. And it comes to a point where the question is can we deal with this problem or do we need to refer to an IBD centre?'*

GEs (generalist and specialist) consider:

- **prevention strategies the responsibility of GPs**, although some would, for example, advise GPs on immunisations required (i.e. live or not) in advance of using biologics
- the **development of complex clinical and medication regimes for the management of IBD patients the responsibility of GEs** (generalist or specialist; ideally the latter but recognising that not all communities have access to tertiary services or centres).

'Low level colitis could be managed appropriately by a GP.
Complicated patients should be managed by a GE.'

Public sector GEs noted they would benefit from these occasions to consider IBD management guidelines and advances in medicine:

- clinical management meetings – held daily/weekly; an opportunity to discuss specific patient needs
- clinical networks meetings – typically gastroenterology-focused with an emphasis on IBD
- journal clubs – where contemporary articles and research publications (national and international) are discussed. Generalist GEs mentioned that the focus of these is broader than IBD but given the complexity of these patients and recognising research advances, IBD was often the topic of conversation. Some GEs who are not party to journal clubs mentioned they *‘read journals in [their] spare time’*)
- clinical research engagement through associations with regional and international universities and research institutions.

Note: Specialist GEs did not reference these opportunities, and those generalists with an interest in IBD mentioned they had retained or fostered links to a tertiary centre, associated opportunities and networks.

All GEs mentioned the benefits associated with attending the following conferences:

- Australian Gastroenterology Week – While the scope of the conference encompasses gastroenterology as a whole, there is a strong focus on IBD management and research findings. Generalist GEs and some specialists (public and private) mentioned this.
- ECCO Annual Conference – All specialist and some generalist GEs are aiming to attend the ECCO annual conference.

IBD guideline suggestions

Specialist GEs see no gaps in information/guidelines that research isn’t addressing, but they perceive a gap in *‘trusted resources’* for GPs and potentially generalist GEs. They feel the following is missing (Figure 23):

- summaries – *‘Preconception and ‘antenatal care’* including *‘simple information for GPs’* (Note: Participants referred to the St Vincent’s fact sheet on pregnancy and IBD and emphasised the need for GPs to understand the relationship with IBD given misconceptions and miscommunications); *‘a table of safe medications’*; *‘screening requirements for those with long-term IBD (e.g. skin cancer checks)’*; *and ‘travel vaccinations’*
- guidance on how to manage non-compliance – *‘Managing young adults can be challenging…high levels of non-compliance.’*
- algorithms (i.e. if this, then do that) – (Note: GEs mentioned algorithms used in ECCO guidelines)
- decision support –
    - clarification of ‘*when to call for advice on the management of IBD patients’* pre or post diagnosis:
        - Note: GEs mentioned that patients are often very sick by the time they see them. Early identification of IBD symptoms by GPs would help reduce the severity of the condition
    - clarification of ‘*when to refer to public services or private services’*

        - Note: In one session, a respondent referred to a private GE transitioning a patient to the public system in response to the complexity of the patient and circumstanced surrounding the need for a multidisciplinary approach and the affordability factor
    - support tools such as decision trees/flowcharts:
        - *'… pushes consideration of that key question you mentioned, how do we manage it, or do we need to push it off to a specialist referral. Those scenarios and that decision – understands the decision-making processes by potentially using something like a flowchart to help work through when it's appropriate/when it's inappropriate.'*
        - Note: Reference was made to algorithms and flow charts used in UpToDate and ECCO, and the need for these to be tailored to *'different scenarios'* (e.g. vaccinations)
    - guidance on when to start/stop steroids
- cycles of care and associated checklists, such as the Aspen Physicians' Crohn's Disease Cycle of Care
- updates on research and contemporary management of IBD
- a central repository/archive of articles containing actual papers or links to papers.

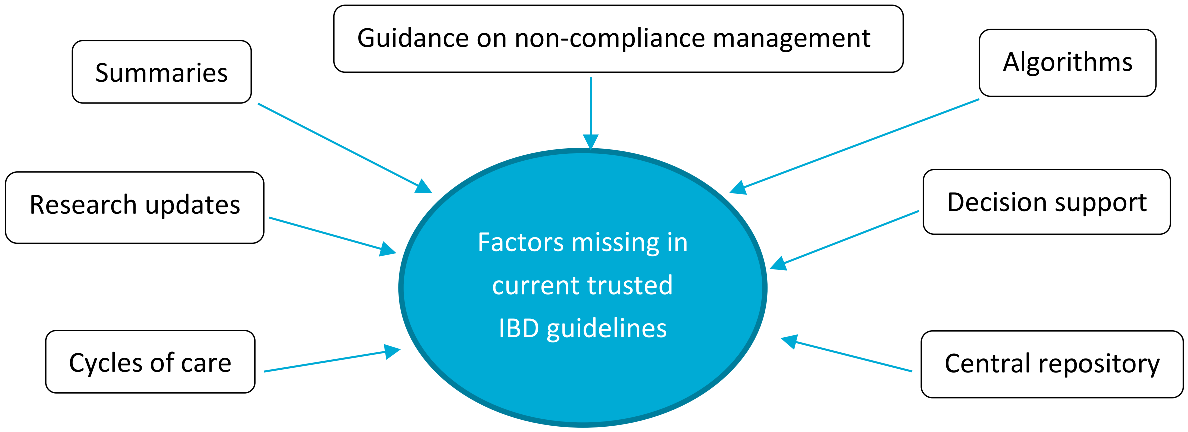


Figure 23: Elements in current IBD guidelines that generalist GEs and GPs feel are missing, according to GEs.
Source: Developed by AGPAL on behalf of CCA.

The GEs (public and private) recognised the increasing number of patients with IBD and the challenges GPs face, including:

- keeping abreast of clinical guidelines when patient numbers in general practice are typically low and of evidence-informed care when advances in the management of IBD are ongoing
- 15-minute medicine and the short window of opportunity to, for example, assess patient need, identify potential IBD, review guidelines, determine tests required, engage with patients and decide on appropriate actions while addressing holistic/comorbidity needs.

Participants felt that awareness needs common to both GPs and generalist GEs are:

- awareness and diagnosis

- preventative care – immunisations and vaccinations; screening (*'I haven't seen a GP who has initiated necessary screening [for IBD patients]'*); (Note: Generalist GEs felt *'preventative care was lacking in training'*)
- management –
    - *'Specialists should come in there, but GPs need to know what not to do.'*
    - *'how to deal with flares'*
    - *'how to check [and manage] infection'*
    - *'when and how to manage children'*
    - *'access to and the management of antenatal patients'*
  - Note: There seemed to be some misunderstandings surrounding conception and pregnancy and how to appropriately manage IBD
- medication management –
    - Participants felt there wasn't good advice on medication management and expressed concerns about GP prescribing:
        - *'side effects and how to manage them'*
        - *'use of MIMMS and patient look-ups'.*

Participants felt that GPs need *'more initial knowledge',* information on therapeutic management regimes, clinical indicators and red flags (what to watch out for), the safe use of medications and when to seek specialist advice and support.

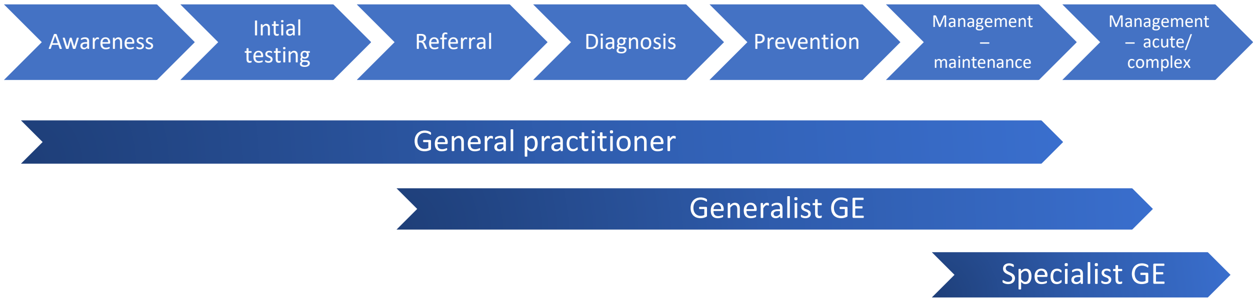


Figure 24: Interpretation of clinical remit.
Source: Developed by AGPAL on behalf of CCA.

Some GEs mentioned that they like to retain the management responsibility of IBD patients. Others recognised that the GP plays a critical role in supporting the patient on a comprehensive and continuous basis, noting that:

- *'I may only see a patient once a year, 'if presenting with an acute flare'* or when '*changes to medications were required'*
- *'Patients required care coordination for multimorbidity'* (i.e. the role of the GP).

Participants felt that clinical guidelines would be more useable if they were configured as a phone app or could be viewed in phone view.

When looking to address gaps in knowledge, participants strongly recommended that we '*don't reinvent the wheel'* but rather link and leverage what currently exists and ensure everything is available to all clinicians in one accessible platform.

Multidisciplinary teams and shared care

Again, when discussing use of clinical guidelines, the conversation extended to multidisciplinary working and shared care:

- *'The GESA guidelines have a heavy emphasis on the wider multidisciplinary team.'*
- *'This presents challenges in the rural and remote settings that have limited access to both specialist services and allied health.'*

GEs recognised the need for good communication:

- the ability to respond in real time to *'desperate calls from GPs'*
- the need for the specialist GE to provide the same message to both generalist GEs and GPs. This was considered to comprise *'good letters'* and *'clinical handover'* and *'GP liaison'* and '*liaison with the IBD nurse',* recognising that this was '*not always as successful as it could be'*.

GEs also recognised the challenges presented to GPs in using the MBS, including *'bulk billing challenges'* and the knock-on effect for patients and GPs. They felt GPs had enough information with which to share the management of patients, noting that the *'development of an initial management plan [GPMP or the like] takes time'. 'Some GPs have an interest and others not.'*

They also commented on the disparity of approach across GPs and generalist GEs:

- Some management is considered *'inadequate'*:
    - '*In my experience rural medicine is not good with the management and care of IBD – both GPs and gastros.'*
    - Note: In some cases this reinforces the perception that the specialist needs to retain the management of IBD patients.

GEs suggested these members of the **extended service delivery team** for low complexity patients:

- dietitians
- psychologists – to mitigate stress related flares
- rheumatologists
- dermatologists (but less so).

Participants noted that some of these team members may be available via hospital services; if not, they are available in the community on a self-funding (including private health insurance) or MBS rebated basis. But participants recognise the limited access to allied health for patients via the use of GPMPs (noting some GPs develop GPMPs with their patients – *'I get faxed copies to sign'* – while others don't) and that some patients and GPs are reluctant to develop Mental Health Treatment Plans (MHTPs) which provide access to MBS funded psychological services, given the stigma attached to a mental health diagnosis.

Suggested members of the extended service delivery team for complex patients include other specialists:

- rheumatologist
- oncologist
- surgeon
- IBD nurse.

Participants felt that a cycle of care, decision trees/flowcharts, supporting checklists and summary sheets, and shared care and sick day action plan tools and templates would be hugely beneficial for all clinicians:

- *'Flowcharts probably would be the most helpful – I mean we all read your articles and, you know, read the abstract and skip to the end results and the flowchart anyway…if you need more detail you can reference that.'*

5.2.3. Health literacy

5.2.3.1. Preliminary survey on patient health literacy

Participants' suggestions for improving the health literacy and awareness of patients, their family and carers include:

- **content** – simple and easy to understand; include only relevant information and in different levels of knowledge (basic versus advanced)
    - *'…Similar to UpToDate, pitched to various levels (e.g. basics and beyond the basics).'*
- **format** – online and printable, phone app, well written websites, centralised, association website, patient specific website, support website and NACC patient information sheets
- **promotion** – by both GPs and GEs, through patient advocacy groups and general patient education:
    - *'Make them available through patient support groups, have them in state and federal health websites, audio versions for those who cannot read'.*

The preliminary survey asked GEs to list factors that would improve patient health literacy and awareness of IBD guidelines. They covered these themes:

- **content** – needs to be current, evidence-based and comprehensive, easy to use/understand, written in simple and different languages and provide basic information about when to seek medical help
- **health literacy** – limit medical jargon, interpret complex concepts, be mindful of the patient's level of health literacy and technology literacy:
    - *'I think guidelines are best used in conjunction with specialist or nurse consultation as otherwise interpretation of risks may cause undue alarm.'*
    - *'Terminology and avoiding medical jargon. May impact patient/doctor interaction if info goes against advice (especially if not ready or interpreting correctly).'*
    - *'No medical jargon, outline basic management and allow patients to understand when to seek medical help.'*
- **promotions** – of known and available guidelines through established networks (GP, social media):
    - *'Making them known and available through established networks such as Crohn's Colitis association, GP networks, social media.'*

5.2.3.2. Focus group/semi-structured interviews

All GEs supported moves to increase patients' health literacy but they had mixed views on whether patients would find having access to clinical guidelines helpful in this regard:

- *'I think it's good that patients have access to the guidelines.'*
- *'The language level might be difficult to understand.'*
- *I don't think patient will misunderstand the guidelines. I think it's more often they don't understand because it's too complicated.'*
- *'I think patients would rather go to Instagram or Facebook or like this group to get [that] information.'*
- *'It's about increasing the level of understanding but minimising the potential harm to the patient.'*

Rather than providing the guidelines, participants felt that using a flowchart to inform shared decision making, alongside patient literature, may be more beneficial.

The GEs use these sources of patient information:

- **Crohn's and Colitis UK website**, which provides:
    - *'a basic understanding of the conditions without the cost of a subscription'*
    - *'useful information written for patients'*
    - *'[information]…written in the language, which is…simpler and easier to understand'.*
    - One participant said: *'I frequently print out the handouts and give [them] to the patient.'*
- **Crohn's & Colitis Australia website**:
    - *'Access to useful information but there is a cost to join.'*

GEs commented that:

- They didn't refer patients on to support groups *'as much as they should'.*
- *'Youth don't want to join meetings but rather use social media.'*
- [There are] *'too many [support groups] out there',* although they recognise '*the online chat rooms/forums seem good.'*

Tools that participants felt could enhance health literacy include (Figure 25):

- a cycle of care for both GPs and patients to follow
- checklists and flowcharts, to inform shared decision-making
- GPMPs or shared care plans ('well day action plans'), to tie everyone together when working to achieve patient goals
- sick day action plans, to educate patients on what to do to prevent a flare, who to reach out to if their condition flares, and what to do in the intervening period
- guidance on side effects of medications –

- *‘As I become a consultant, now I realise that it is important to let them be aware of it.’*
- *‘I’d rather they know the side effects through proper information, rather than going on to Google and some…website.’*

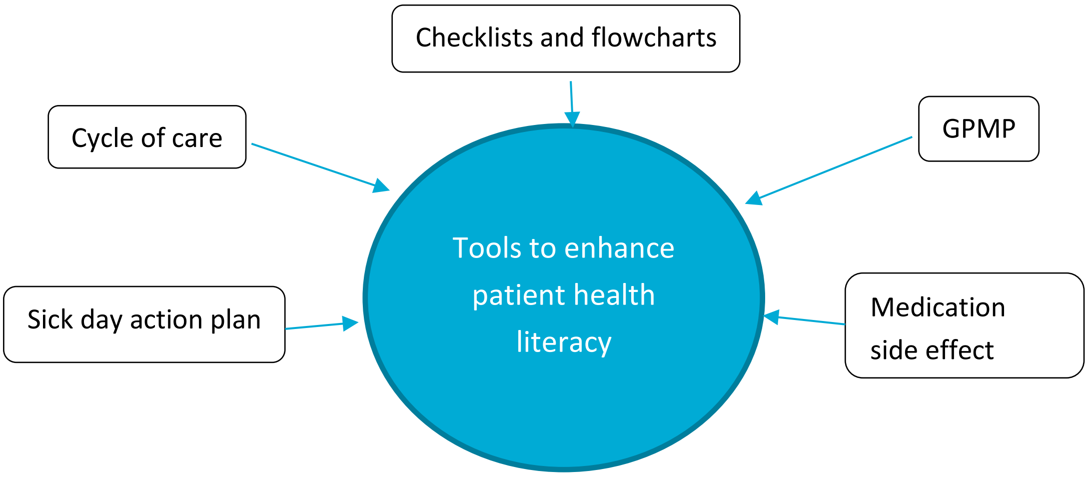


Figure 25: GEs’ suggestions for tools that would enhance patient IBD health literacy.
Source: Developed by AGPAL on behalf of CCA.

5.2.4. CPD, education and training

5.2.4.1. Preliminary survey on CPD preferences

The preliminary survey asked participants to clarify and prioritise any CPD needs for IBD management. Most responses suggested that there is already a lot of CPD for GEs through meetings and other resources. They suggested some additional topics: new emerging diet information, reliable patient surveys, summary of main content/new content each month, and continuous updates.

Participants established that their preferred CPD mode of delivery is face-to-face workshops, followed by online webinars/workshops and eLearning modules and resources (Figure 26). An additional suggestion was for professional bodies to send GEs email updates.

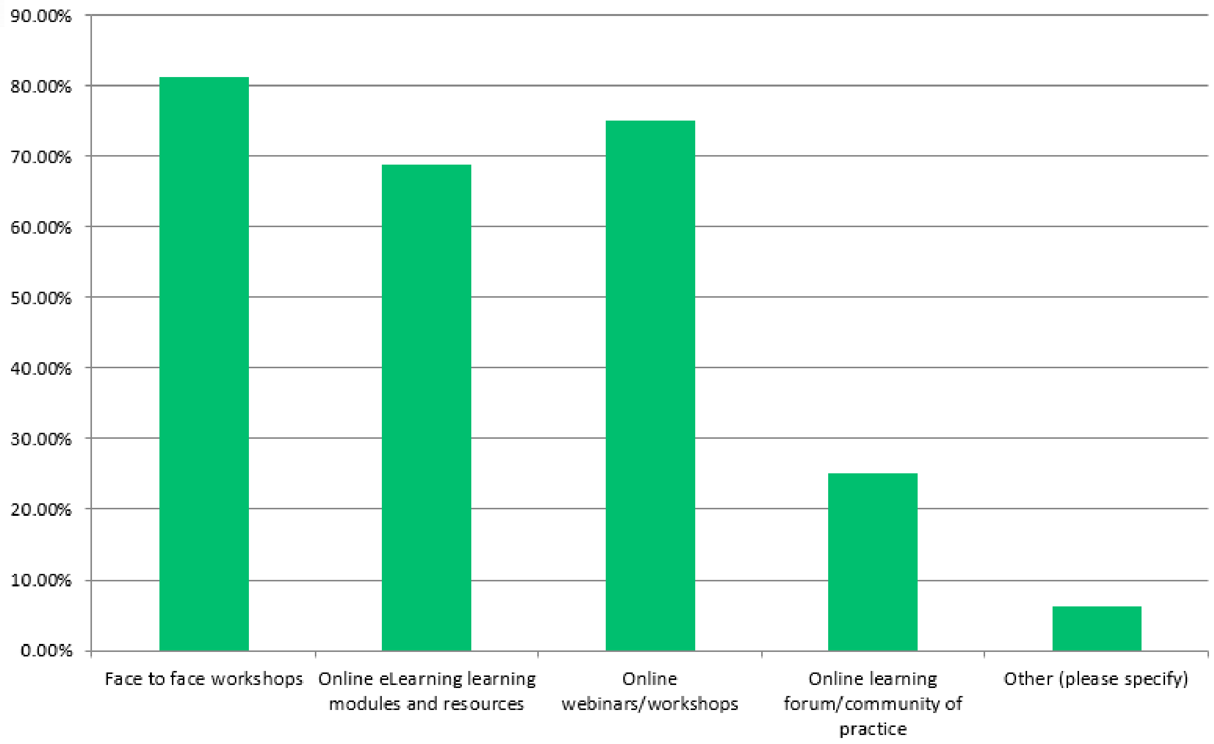


Figure 26: GEs' preferred CPD modes of delivery.
Source: Developed by AGPAL on behalf of CCA.

5.2.4.2. Focus group/semi-structured interviews on CPD

GEs felt they benefitted from multiple opportunities for CPD, education and training, either sponsored by a pharmaceutical company or not, and that it is '*often difficult to choose'* between events and education.

GEs identified these educational opportunities:

- ECCO annual internal conference
- Australian Gastroenterology Week conference
- journal clubs
- dinners and forums
- clinical network meetings and events.

In particular, generalist GEs referenced:

- the *'IBD School'* – an annual eight-week program of 1.5 hour online sessions focused on GE and IBD nurse education and updates in the management of IBD
- Australian Gastroenterology Week (AGW) –
  - focuses on all gastrological conditions and strongly emphasises contemporary management of IBD
  - open to both GEs and GPs with a discount for GP participants:
    - *'The GP sessions were very good.'*
    - *'Joint sessions provide the opportunity to establish networks and relationships between GPs and GEs.'*

Note: While traditionally held face-to-face, AGW was successfully held online in 2020 due to the COVID-19 restrictions.

GEs referred to the CPD points requirements placed on GPs, noting that while GPs are encouraged to attend the AGW conference, GPs' attendance at the ECCO conference is not appropriate.

GEs agreed there is a need to raise awareness among GPs of the signs and symptoms of IBD. Some felt that a lack of awareness and early identification of a patient's needs and potential IBD diagnosis from a GP may make the patient's need more severe.

When asked to distinguish between the education and training needs of GPs and those of GEs, GEs noted there is common ground between GPs and generalist GEs (distinct from specialist GEs) and that the current environment may well *'not be meeting GP needs'*.

GEs welcomed the opportunity to meet with interested GPs either through education sessions or within local clinical networks to *'bring us together in the same room…a safe room'.*

When asked to consider the common education and training needs of GPs and generalist GEs, participants identified (Figure 27):

- **knowledge** of where to go for *'one source of truth'* (or at least a repository of resources)
- **initial investigations and testing regime** –
    - What could/should be undertaken by a GP in advance of a referral?
    - What could/should be undertaken by a generalist GE in advance of a referral to a specialist?
- **diagnosis** – differentiating between IBS and IBD (and associated testing) and distinguishing between the different tests that GPs and GEs can undertake (e.g. access to publicly funded faecal calprotein testing)
- **referrals** – What constitutes a good clinical referral that would best inform triaging? How and when to refer (noting the where is determined by availability of services and local referral pathways, patient circumstances and choice)? What information does a GE or specialist need when escalating care (e.g. clinical history; examination/preliminary tests conducted and results; comorbidity impact and implications; vaccination history etc.). It was felt that a simple *'checklist or template would be ideal'.* How to manage patients with suspected or acute episodes in the intervening period?
- **prevention** – immunisations and vaccinations (recognising this is the responsibility of GPs); *'live versus not'*; *'travel requirements'*; screening requirements, opportunistic or cyclical
- **therapeutic management** – including *'What will and won't cause harm?'*; infections (*'How to check for infection, what to do and when to refer'*); and management of an acute flare (*'What will and won't cause harm?', 'de-escalation. How to reduce causation factors?')*
- **medicines** – utilisation (what GPs can prescribe as distinct from what general GEs and specialist GEs can prescribe respectively); the safe use of medications (e.g. steroids); side effects and red flags (e.g. biologics and synth); *'conflicts with other complicated medications'*; appropriate management of a flare
- **updates** on IBD management, medication and information

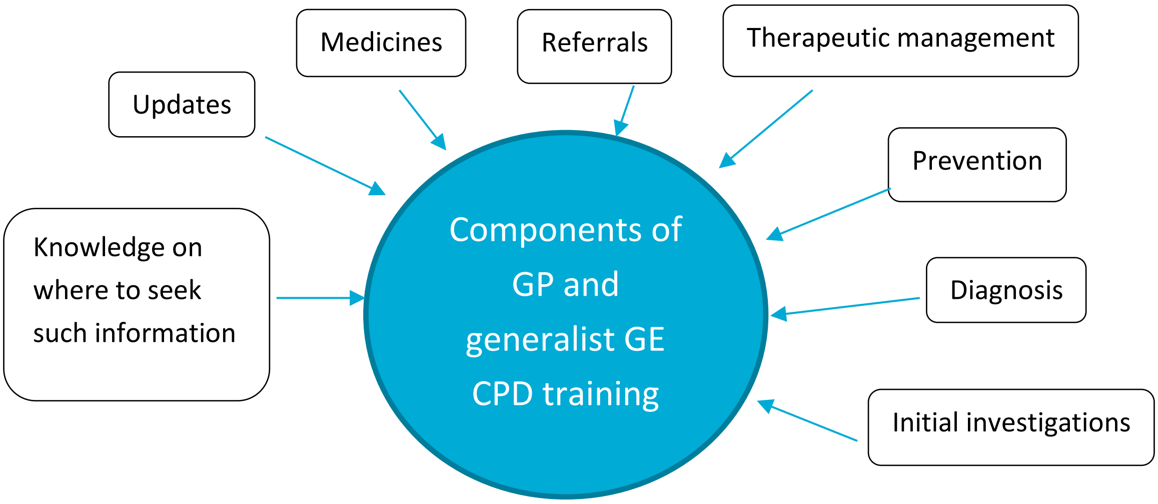


Figure 27: Components of GP and general GE CPD training.
Source: Developed by AGPAL on behalf of CCA.

One suggestion was to develop '*an education CPD framework'* distinguishing roles and learning needs, which would be helpful for all clinicians involved in the management of IBD patients.

Participants suggested case studies and education in specific cohorts/scenarios including:

- **sub populations** – paediatrics, young adults, pregnancy, elderly people – recognising the increase in prevalence and complexity of comorbidity: *'I think I'm seeing at least one patient…who is above 65 years old every month with a new onset or, yeah, new onset of IBD.'*
- **international travellers** – *'Travel medicine and questions about vaccination safety in people who are taking immunosuppression'* and '*the involvement of the ID [infectious disease] physicians in the care of [the patient].'*
- **Aboriginal and Torres Strait Islander peoples** – Interestingly, participants saw limited need in the Aboriginal and Torres Strait Islander communities: *'I worked in Darwin for about two years and I haven't come across any IBD among the Aboriginal population'*; *'The visiting gastroenterologist who visits there for the last 10 years has never seen one either.'*
- **comorbidities** – immunosuppressed, pain management, bone health.

One suggestion was to adopt a problem solving approach supported by a decision tree/flow chart rather than a dialogic approach:

- *'If we were to build something in education and training that the scenario…to say, and then pushes consideration of that key question you mentioned, how do we manage it, or do we need to push it off to a specialist referral? Those scenarios and that decision…understands the decision-making processes by potentially using something like a flow chart to help work through.'*

Participants suggested these modes of delivery:

- ‘*media and online learning’* to deliver *‘interactive or not’* training (i.e. online webinars and workshop or eLearning modules)
- opportunities for ‘*face-to-face education and networking*’ either at a national level (e.g. Australian Gastroenterology Week conference) or at a regional level at *‘workshops or network meetings’.*

Participants had mixed views on the benefits of case studies:

- *‘There’s only a finite amount that you can convey as a message in a case study. Every patient is different. The chance of one case study [answering the exact question you’re asking] would be somewhat low.’*
- *‘Case studies are good for actually very complex cases where the management is highly individualised.’*

5.3. Post survey

The review team invited GPs and GEs to complete a post focus group survey of four open-ended questions.

The first question asked participants whether they had anything else to share about the project, CPD and resources. Ten of the 22 participants had no further comments. Six participants reinforced what was said in the focus groups around content and format of guidelines and CPD. There was one suggestion of combined education sessions which would foster GP and specialist familiarity. A suggestion for IBD CPD delivery, other than what was earlier reinforced, was a ‘hot topics’ type of education video to be watched at leisure.

‘1) 40 points CME activity is mandatory to attract max[imum] number of attendance [especially] it is very activity by AGPAL. 2) Preferably mix up of F/F workshops including psychologist and dietitian with prominent gastroenterologist, followed by online modules. 3) Offering printed downloadable educational leaflets to be given to patients. 4) The activity should cover awareness, early detection, diagnosis, managing acute presentation, managing emergency, maintenance therapy, medications update, collaborative team care.’

‘Earlier detection, implementation of treatment strategies, better support would be beneficial including being linked with support groups online. Physical and psychological care need not be addressed. Stress management is an important issue. Practical issues such as management of incontinence and urgent use of toilets could be facilitated by increasing public awareness.’

The second open-ended question asked where would be best to host IBD guidelines and related online learning resources. GESA was the most suggested platform, with HealthPathways and RACGP tying for second. Additional suggestions were CCA, a platform specifically for GPs, ACCRM, Best Practice, eTG, practice software, Medical Director, online and in a phone app.

When the survey asked participants about any insights they had gained from participating in this project, four themes emerged:

- **awareness –**
    - *‘It gives me an opportunity to appreciate the knowledge gap pertinent to GP.’*
    - *‘The desire from GPs to have greater awareness surrounding the management of IBD.’*
    - *‘Became more aware of guidelines available, internationally, and online.’*
    - *‘There are different methods for accessing resources for GPs and gastroenterologists.’*
    - *[Made me] ‘think about IBD more than before.’*
    - *‘There is a lack of resources for primary care.’*
    - *‘GPs are left out of shared care planning.’*
    - *‘Shared decision-making’*
- **cohesive responses –**
    - *‘I think from the discussion that the suggestions I have made are similar to those of other participating doctors.’*
    - *‘That other people mostly experience the same presentations and broadly feel the same about the situation.’*
    - *‘That we are all still dealing with the same dramas.’*
- **differences** –
    - *‘There is a variability in GPs’ role in IBD.’*
    - *‘Guidelines are utilised differently between GPs and gastroenterologists.’*
- **other statements** –
    - *‘Great to collaborate across disciplines and share information…crucial to ensure we’re reading from a common plan or source!’*
    - *‘Glad that I’m close to a tertiary hospital.’*
    - *[Want] ‘comprehensive resources’.*

The last open-ended question of the post survey asked participants to provide feedback on the IBD GP Aware project review process. The review team received an overwhelmingly positive response about the inclusion and input of GPs and GEs, the project as a whole, and specifically the delivery of the focus groups.

6. Conclusions

The IBD GP Aware project was a chance for GPs and GEs to inform the development of:

- a promotional campaign about awareness and utilisation of IBD guidelines
- a co-designed CPD program to increase capacity within general practice and the broader health system to deliver evidence-based care.

The IBD GP Aware Project literature review published in November 2020 highlights the vast range of guidelines on the management of IBD that are available to clinicians. Engaging with the project helped to raise awareness of clinical guidelines: feedback from all participants highlights the need for a central repository of guidelines and literature – 'one source of truth' that could be integrated with or linked to systems that GPs and GEs use.

Interestingly, 44% of GPs surveyed said they never refer to IBD guidelines (this raises the issue of patient safety and quality), while GEs always do. But where the two professions look for guidance is distinct and different: when utilising guidelines, GPs prefer national GESA guidelines on the management of IBD while GEs look to Europe and ECCO guidelines for the latest guidance on evidence-informed care. Similarly, GEs may look to CCA and United Kingdom consumer groups for information for patients.

All clinicians agree that the condition of IBD is complex and as such the guidelines are complex. Further, they agree that care should be tailored to address patient need at a specific point in time.

While specialist GEs who commonly use the ECCO guidelines are familiar with the layout and style, GPs and generalist GEs find the GESA guidelines very lengthy and often difficult to navigate within the time constraints of the patient consultation (this reflects their unfamiliarity with the guidelines). While the guidelines may inform clinical decisions, they don't appear to inform shared decision-making between patient and GP or patient and GE.

Typically, IBD patient numbers in general practice are low. This creates a tension for GPs, which includes the need to:

- deliver quality care within the limitations of the general practice setting and constraints of the MBS
- balance personal investment in CPD for the benefit of a very small yet potentially complex number of patients, with personal investment in CPD that would address the needs of the majority.

Both GPs and GEs recognise that the prevalence of IBD is increasing and that early identification and evidence-informed management are critical to person-centred care and optimal health outcomes.

AGPAL looks forward to translating these results into purposeful education and training resources for the benefit of patients and clinicians.

7. Recommendations

This report provides valuable foundations for the future development of a promotional campaign on GP awareness and utilisation of IBD guidelines and a CPD program. Some consistent themes and general recommendations emerged around these topics:

IBD guidelines

Recommendation 1 – Re-structure and re-format IBD guidelines rather than re-write them.

Rationale: Approaches to optimise the utilisation of the best practice guidelines don't seem to warrant a re-write of the GESA guidelines, but rather:

- a re-structuring of the guidelines (i.e. into bite size summaries at each stage of the pathway) and development of downloadable summaries
- a re-formatting of the web content to ensure it follows the typical patient journey while addressing the needs of different cohorts of patients.

Recommendation 2 – Develop a range of tools to support IBD guidelines that would help patients , GPs and GEs in shared decision-making and the development of shared care arrangements.

Rationale: Patients, GPs and generalist GEs need to understand the long-term nature and structure of care required to optimise health outcomes. Communication is critical. What appears to be missing is a range of tools and resources to strengthen the provision of evidence-informed care, facilitate patient engagement and shared decision-making, and promote multidisciplinary team-based care and the establishment of shared-care arrangements.

There is unilateral support for developing:

- an algorithm/decision tree/flow chart that reflects the patient journey and references the relevant summary guidance and patient equivalent to inform decision-making at each stage
- a cycle of care/checklist encompassing testing, prevention and management components
- guidance on a quality referral (GP to GE, GE to specialist) to better inform triage
- a shared care plan template that enables comprehensive and continuous care (reflecting the cycle of care, encompassing all allied health options and including both self-management and social care needs in addition to the clinical regimen and care coordination/case management responsibilities)
- guidance on when and how to escalate care to ensure flare-ups and complications (e.g. infections) are managed appropriately and in a timely manner
- guidance on the commonly used MBS item numbers in general practice and their relationship to the cycle of care, shared care plan and medication review
- a sick day action plan template developed with patients and clarifying what to do on a bad day
- guidance on access to and the safe use of medicines.

Recommendation 3 – Develop a tool that GPs can use alongside the patient for tailored and informed decisions.

Rationale: Participants feel that such a tool would benefit both clinicians and consumers. Participants anticipate that adopting a stepwise approach, enabled by a flowchart and supporting summary guidance at each decision point, would help GPs and patients to learn as they go and make tailored and informed decisions.

Recommendation 4 – As a whole, promote IBD guidelines for GP use.

Rationale: There is variability in the use of clinical guidelines on the diagnosis and management of IBD. Both GPs and generalist GEs would benefit from a better understanding of guidelines to optimise the care of IBD type patients in support of the quadruple aim.

CPD

Recommendation 5 – Develop specific education and training on the different components of IBD management.

Rationale: Participants believe it is important to have education and training on differentiation, identification, diagnosis, prevention and management of IBD within the general practice setting, including medication management, within the structure of a long-term cycle of care.

Recommendation 6 – Include scenarios and case studies to inform users of the complexity of IBD.

Rationale: Scenarios and case studies can be utilised to bring to life the challenges of managing specific cohorts of patients, the complexities of IBD, age related conditions and comorbidities and so on.

Recommendation 7 – Offer a mix of CPD delivery modes for personal learning and broader engagement.

Rationale: GPs and GEs prefer a mixed mode CPD approach that provides both personal learning and broader engagement across the community of practice (GPs and generalist GEs). This approach would encompass an eLearning platform of eLearning modules/podcasts, supported by collaborative workshops (online or face-to-face) to reinforce and extend the learning, and provide an opportunity for dialogue and the testing of understanding through questioning subject matter experts and guest speakers.

Recommendation 8 – Allocate CPD points for completion.

Rationale: While not a primary driver for all participants, GPs would benefit from the allocation of CPD points.

Recommendation 9: Tailor and contextualise CPD for the targeted audience.

Rationale: Clearly any CPD needs to be developed with and tailored to the audience, and potentially encompass four components:

- patient stories and patient/team partnerships
- optimal care and clinical management
- the process of multidisciplinary teamwork and shared care
- leadership skills – personal agency, health coaching etc.

It also needs to be contextualised to reflect rural and remote communities, which have distinct and different circumstances from urban or metropolitan regions.

8. Added value

As an aside, it is worth noting that a number of GP and GE participants, including specialist GEs, commended the approach the review team adopted, stating that they had learned additional information and identified new relevant clinical guidelines through the preliminary survey. They also said they valued the opportunity to collaborate with peers outside of their normal clinical networks to inform the development of CPD and IBD campaigns.

9. Next steps

The findings and conclusions in this report finalise the Phase 1 activity (i.e. the identification of barriers and enablers to the effective use of current IBD management guidelines and relevant gaps in information). These results will now inform Phases 2 and 3 activities:

- Phase 2 – Increase GP and GE awareness of IBD management guidelines
- Phase 3 – Increase GP and GE utilisation of appropriate guidelines for the differentiation, prevention, diagnosis and management of IBD.

10. Limitations of approach

The review team acknowledges limitations of its approach:

- clinician fatigue exacerbated by frequent changes in the health system operating environment, concerns regarding the onset of a new wave of Covid-19, and their inability to focus on 'non-clinical' related activity (i.e. activities not immediately and directly related to patient needs)
- the short window of opportunity provided to secure the clinical engagement of GPs and generalist GEs at a very busy time of year (recognising the run-up to and post the seasonal break).

The review team considered direct engagement with stakeholder representative bodies (e.g. professional bodies, hospital-based GP liaison teams, PHN GP advisory committees, IBD related clinical networks etc.) and consumers to be out of scope. Engagement with these stakeholders may have secured more clinical engagement and/or offered additional insight.

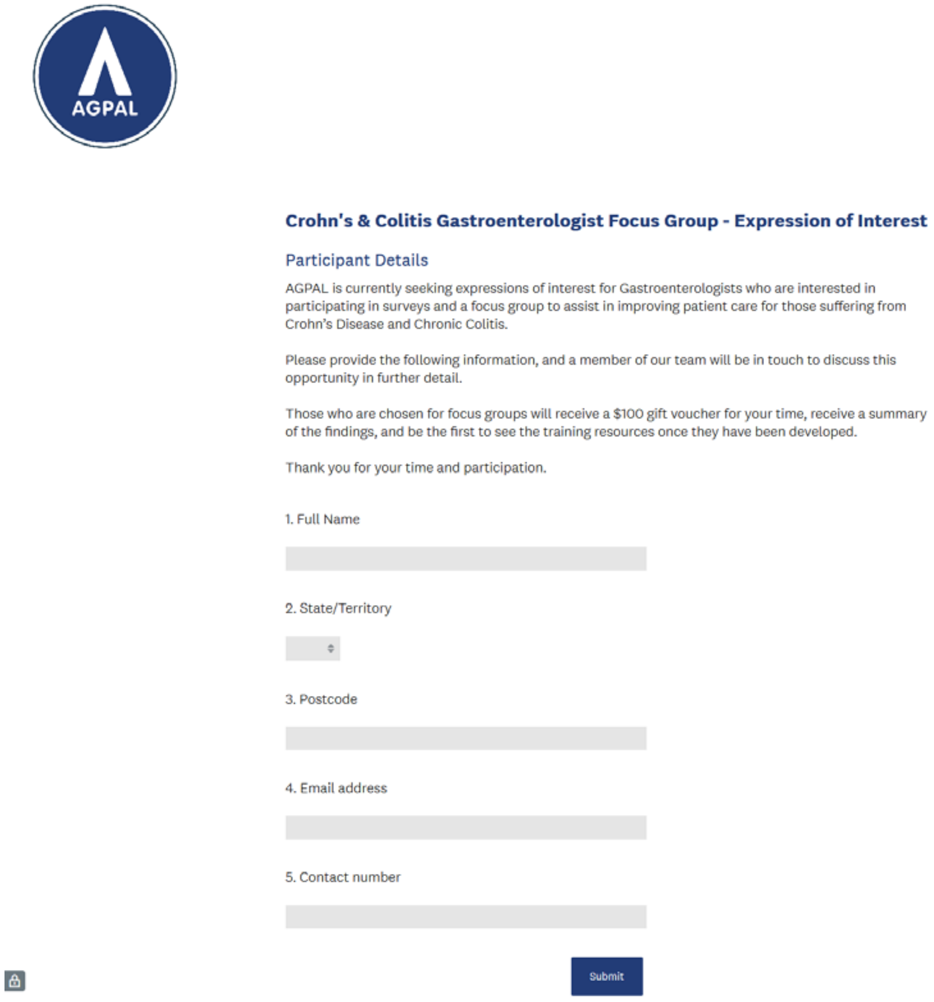
The review team is however confident that the results of the GP and GE engagement activity are robust:

- Initial results (at 7 December 2020) of the preliminary survey were considered, challenged, corroborated and expanded on (as appropriate) in focus group and one-on-one semi-structured interview activities.
- The findings of preliminary focus groups were tested, corroborated and expanded on in subsequent focus groups to the point of saturation of findings.
- Participants were provided a final opportunity to provide afterthoughts, additional information, advice and guidance, following focus group or one-on-one semi-structured interview attendance.

11. Acknowledgements

AGPAL acknowledges the support of CCA and GESA in recruiting participants. We also acknowledge the PHNs for distributing the expressions of interest to support the GP recruitment. We especially wish to acknowledge and thank all GPs and GEs for participating in our review, making a valued contribution, being willing to openly share opinions, information and insights, and providing rich data that will invariably inform the development of CPD and IBD campaigns.

12. Supplementary files and appendices



Crohn's & Colitis Gastroenterologist Focus Group - Expression of Interest

Participant Details

AGPAL is currently seeking expressions of interest for Gastroenterologists who are interested in participating in surveys and a focus group to assist in improving patient care for those suffering from Crohn's Disease and Chronic Colitis.

Please provide the following information, and a member of our team will be in touch to discuss this opportunity in further detail.

Those who are chosen for focus groups will receive a $100 gift voucher for your time, receive a summary of the findings, and be the first to see the training resources once they have been developed.

Thank you for your time and participation.

1. Full Name

2. State/Territory

3. Postcode

4. Email address

5. Contact number

Appendix 1: Expression of interest form for the IBD GP Aware project.
Source: Developed by AGPAL on behalf of CCA.

Note: Appendix 2-6 can be found in a separate document upon request

Appendix 2: Patient information and consent can be found in document *Appendix 2 Participant information and consent.*

Appendix 3: The GP preliminary survey questions can be found in document *Appendix 3 GP preliminary survey.*

Appendix 4: The gastroenterology preliminary survey questions can be found in document *Appendix 4 GE preliminary survey.*

Appendix 5: Emails that were sent to GPs and GEs after completion of the EOI can be found in document *Appendix 5 emails after EOI.*

Appendix 6: The post focus group survey questions can be found in document *Appendix 6 post survey*.

Appendix 7: The post focus group survey email included the following text:

Hi,
Thank you for participating in the AGPAL Crohn's and Colitis Focus Group. Your feedback and opinions were valued and appreciated. Please see below the link to a very short final survey, giving you the opportunity to provide any final feedback or comments on the focus group topics that were not shared earlier.
Please click on the link below to access the final survey:
https://www.surveymonkey.com/r/RFR28RY
If you would please be so kind to return any final comments and feedback by **COB Tuesday 12 January 2021**.
Regards,

IBD guidelines	**Brief name**
2018 management of paediatric ulcerative colitis – Parts 1 and 2, ESPGHAN	ESPGHAN: Paediatric UC
ACG clinical guideline: management of Crohn's disease in adults, American College of Gastroenterology	ACG: CD management
Acute severe colitis (ASC) pathway: guide to daily inpatient management decisions, New Zealand Society of Gastroenterology	NZSG: Acute severe colitis pathway
All IBD results on UpToDate	UpToDate: IBD
British Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults, British Society of Gastroenterology	BSG: IBD management
Clinical manifestations, diagnosis, and prognosis of Crohn disease in adults, UpToDate	UpToDate: Adult CD
Clinical manifestations, diagnosis, and prognosis of ulcerative colitis in adults, UpToDate	UpToDate: Adult UC
Clinical presentation and diagnosis of inflammatory bowel disease in children, UpToDate	UpToDate: Children IBD
Clinical update for general practitioners and physicians – 2018, GESA	GESA: 2018 Update
ECCO–ESGAR guideline for diagnostic assessment in IBD part 1: initial diagnosis, monitoring of known IBD, detection of complications, ECCO: Maaser et al	ECCO: Part 1 Known IBD management
ECCO–ESGAR guideline for diagnostic assessment in IBD part 2: IBD scores and general principles and technical aspects, ECCO: Sturm et al	ECCO: Part 2 IBD scores and principles
eTG: Gastrointestinal – IBD, Therapeutic Guidelines	Therapeutic guidelines: IBD
Fact sheet: diet in inflammatory bowel disease (IBD), GESA	GESA: Diet fact sheet
Gastroenterologist fact sheet: pregnancy, fertility and inflammatory bowel disease, GESA	GESA: Pregnancy fact sheet
Gastroenterology, St Vincent’s Hospital	St Vincent’s Hospital
IBD acute ulcerative colitis medical management v.2.0, Seattle’s Children	Seattle’s Children: IBD acute UC
IBD and bowel disorders guidelines, American Gastroenterological Association	ACG: IBD and bowel disorders
IBD assessment and management, SpotOnHealth HealthPathways	HealthPathways: IBD
IBD Standards Core Statements, IBD UK	IBD UK: Core statements
IBS4GPs – Diagnostic Online Tool for GPs	IBS4GPs tool
Inflammatory bowel disease (IBD): checklist for the prevention of infection, ECCO	ECCO: IBD infection
Inflammatory bowel disease in adolescents, RACGP	RACGP: IBD in adolescents
Inflammatory bowel disease toolkit, RCGP	RCGP: IBD toolkit
Inflammatory bowel disease, Queensland Health	QLD Health: IBD
Inflammatory bowel disease, Sydney Gut Clinic	Sydney Gut Clinic: IBD
New standards for IBD aim to improve patient experience and outcome, Guidelines in Practice	Guidelines in Practice: IBD standards
Nutrition and dietary management for adults with inflammatory bowel disease, UpToDate	UpToDate: IBD nutrition and diet
Nutrition and IBD for dietitians, Gut Smart	Gut Smart: Nutrition and IBD

Overview of the management of Crohn disease in children and adolescents, UpToDate	UpToDate: Children CD
Paediatric Gastroenterology Clinical Network: Management of inflammatory bowel disease in children and adolescents in New Zealand – a clinical guideline, Paediatric Society New Zealand	PSNZ: IBD in children and adolescents
South West London Inflammatory Bowel Disease Pathway, SWL IBD Medicines Optimisation Clinical Network	SWL IBD: IBD Pathway
UC and CD management and treatment algorithms, ECCO	ECCO: UC and CD algorithms
Updates in the management of inflammatory bowel disease during pregnancy, MJA	MJA: Pregnancy IBD Update
World Gastroenterology Organisation global guidelines inflammatory bowel disease: a global perspective, World Gastroenterology Organisation	WHO: IBD

Supplementary Table 1: IBD guidelines presented to GPs and GEs for awareness and utilisation.

Source: Developed by AGPAL on behalf of CCA.

13. References

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