



Inflammatory Bowel Disease National Action Plan Consultation Summary

A background document for the
IBD National Action Plan
December 2018

Crohn's & Colitis Australia (CCA), in conjunction with the Australian Government Department of Health (the Department), undertook a range of consultation activities in 2018 to inform the development of a National Action Plan for people living with inflammatory bowel disease (IBD). A summary of the 2018 consultations is provided in this document and builds on the consultations undertaken prior to 2018 by both CCA and DH.

CCA is continuously gathering consumer and IBD stakeholder information through its activities and various media channels. The key additional consultations that were undertaken to inform IBD National Action Plan were:

1. National Roundtable Workshop in June 2018
2. Stocktake of Inflammatory Bowel Disease Healthcare Improvement Activities
3. Public and stakeholder comment on the draft IBD National Action Plan
4. Meetings of the multidisciplinary Scientific, Medical and Quality of Care Advisory Committee
5. Concurrent survey of IBD patient experience of health care

1. National Roundtable Workshop in June 2018

The Department in partnership with CCA hosted an IBD Roundtable Workshop involving key industry and non-government stakeholders on 19 June 2018 at the Melbourne Airport precinct.

The purpose of the roundtable was to inform the development of a National IBD Action Plan. Previous work undertaken by CCA was presented to the roundtable to promote discussion and provide a starting point for an action list. Participants worked in four small groups to develop a list of priority actions to improve IBD care in Australia. A simplified weighting exercise was then used to rank the suggested actions.

Priorities identified

The roundtable identified more than 20 actions for inclusion in a National IBD Action Plan. There was not time for each group to rank each action; however groups were asked to start with the ones they expected to rank most highly. There were 12 actions, or groups of actions, that were ranked as the highest priority by participants. A full list of the actions identified is included in **Appendix 1**. The 12 priority actions identified were:

1. Increased access to specialist IBD nurses (action 23)
2. Increased funding for health hotlines for both patient and GP (action 14) and improved communication pathways for GPs to information/hotlines (action 8)

3. Increased administrative resources to support case-workers in IBD clinics (action 16)
4. Greater access to allied health (action 17), including increasing the number of MBS funded visits for allied health (action 11); and improved credentialing and education across all areas of allied health (action 10)
5. Funding of therapeutic drug monitoring (action 3), including funding of faecal calprotectin testing (action 2)
6. Establish clearer GP referral guidelines and protocols (action 9)
7. Improved consumer knowledge (action 12)
8. Establish multi-disciplinary teams for IBD patients (action 18)
9. Improved credentialing and education across all areas of allied health (action 10)
10. Support for practice management software (action 1)
11. Increased investing, clinical trials and audit of paediatrics (action 4)
12. Explore the potential for effectiveness of medical home – funds bundling. (action 7)

Participation

The following representatives participated in the roundtable:

Dr George Alex	Royal Children's Hospital Melbourne
Ms Cassandra Anslow	Consumer
Dr Ray Boyapati	Gastroenterologist - Australian Inflammatory Bowel Disease Association, Gastroenterological Society of Australia
Ms Stephanie Buckton	Gastroenterology Nurses College of Australia
Ms Jan Donovan	Consumer Health Forum
Dr Loretta Gya	College of Nursing
Dr Simon Knowles	Australian Psychological Society
Mr Wayne Massuger	Project Manager Crohn's & Colitis Australia
Ms Jacinta McDonald	Australian Government Department of Health
A/Prof Antonina Mikocka-Walus	Deakin University
Dr Gregory Moore	Board Director Crohn's & Colitis Australia
Dr James Moore	Colorectal Surgical Society Australia and New Zealand, Royal Australian College of Surgeons
Dr Reme Mountifield	Gastroenterologist - Australian Inflammatory Bowel Disease Association, Gastroenterological Society of Australia
Ms Amy Page	Pharmaceutical Society of Australia
Professor Paul Pavli	Board Director Crohn's & Colitis Australia
Ms Liz Purcell	Dietitians Association of Australia
A/Prof Leanne Raven	CEO Crohn's & Colitis Australia
Ms Anita Reilly	Consumer / Board Director Crohn's & Colitis Australia

Mr Sheridan Rodda	The Society of Hospital Pharmacists of Australia
Ms Nicole Rutter	Public Health Association Melbourne
Dr David Scott	Gastroenterologist (Regional)
Ms Denise Sheard	Chronic Illness Alliance
Ms Merran Spargo	Paediatric IBD Nurse, The Children's Hospital at Westmead
Professor Nigel Stocks	Royal Australian College of General Practitioners
Mr Kevin Thompson	Australian Government Department of Health
Mr Hugh Whittaker	Consumer

Supporting information

In developing the actions above, participants in the Roundtable worked in four groups to consider the issues and potential responses. The CCA background paper was used as a reference by a number of groups. Discussion on IBD issues and possible responsive actions are summarised in **Appendix 2**

2. Stocktake of IBD Healthcare Improvement Activities

The Stocktake of IBD Healthcare Improvement Activities is provided as a detailed separate background document for IBD National Action Plan. It is important to note that in terms of consultation, important communication occurred in relation to both what is currently being provided and the gaps that exist in current service provision for IBD health care in Australia. Information was predominantly provided by health service providers. The survey collected information on 77 reported activities from 20 respondents. A further five respondents indicated that there were no improvement activities to report in their jurisdiction or site. Responses were not received from WA or ACT. Activities reported through the survey generally related to priority areas identified through the roundtable and are shown in full in the separate background document.

3. Feedback on the draft IBD National Action Plan

The draft version of the IBD National Action plan was made available on the CCA website in November 2018 for public comment and a process for feedback to CCA was established. Notification of the opportunity to review and provide feedback was made via email to thousands of stakeholders and people living with IBD, including health professional groups, governments, hospitals, general practitioners, and Primary Healthcare Networks. General notification was made through various social media channels.

CCA received more than 50 separate feedback issues which were considered by the Scientific, Medical and Quality of Care Committee and incorporated into the IBD National Action Plan as advised by the committee.

Examples of feedback included:

- Lack of reference to rural and remote including involvement by rural generalist and internal medicine consultants
- There should be an emphasis as well on up-skilling community and general gastroenterologists
- Consider the 'hand-back' of routine monitoring to primary care to free up specialist resources for early intervention
- Including mention of the importance of timely, quality surgical care would be appropriate to reflect the importance of this in the management of IBD.
- Concern that there is no call for increased research funding i.e. given that IBD remains an incurable disease group only controlled in a subset of patients with significant side effects and its impact on quality of life
- Further work is needed to build the evidence base related to regional IBD prevalence, treatment and service needs in order to help better address these issues.
- Consider adding an action plan for implementation of pilot of IBD pharmacist roles in multidisciplinary teams
- Can you include an area on prevention? There may not be strong data in this area but there must be something - education of the general public about risk reduction/prevention in early childhood?
- We recommend that evaluation of the plan includes additional measures related to patient experience of care, patient reported outcomes and clinical outcomes. We further recommend the addition of health economic evaluations and process evaluation of how this plan is implemented.
- Add explanatory sentence about the difference between local and not local helplines
- Was an app (for iPhone etc.) considered in the consultations and feedback as part of the consumer knowledge gaps? I feel this would be really useful in self-management.
- Include more of a description of what you mean by a personal action plan and the difference between this and GP Medicare chronic disease plans.
- Add explanatory sentence about the difference between local and not local helplines
- In relation to the "Improvement of nutritional status (screening tool)" this desperately needs to be improved as a first line
- Various complimentary comments on the quality and readability of the plan

4. Meetings of the multidisciplinary Scientific, Medical and Quality of Care Advisory Committee

This committee is made up of a range of healthcare clinicians and academics such as nurses, gastroenterologists, dietitian, psychologist, paediatric gastroenterologist and researchers. The committee met by video conference several times throughout the year to consider the development of the IBD National Action plan and provide a range of different points of view on content and feedback received. In particular the committee adjusted the plan according to the feedback received in response to the draft plan circulated for public feedback.

5. Concurrent survey of IBD patient experience of health care

In addition to the consultation activities described, CCA undertook a concurrent survey of the experience of health care for people living with IBD. The *My IBD Experience Research Report* describes the findings of this large scale survey (available at: <https://www.crohnsandcolitis.com.au/ibdqoc/>). This research was undertaken by CCA in collaboration with Deakin University. Over 1000 people living with IBD responded to this survey providing data on the lived experience of IBD care. It informed the IBD National Action Plan with a substantial dataset of patient /consumer information including specific information on how to improve health care for people with IBD. The findings were consistent with many of the priority issues identified at the National Roundtable Workshop such as:

- The need for multidisciplinary care such as nurses, psychologists, dietitians and pharmacists
- Poor access to responsive care, plan of what to do if your condition deteriorates and helplines
- Lack of specialised knowledge about IBD among some healthcare professionals
- Differences in the quality of care delivered depending on the model of ongoing care and corresponding multidisciplinary resources.

Appendix 1 Full list of roundtable proposed actions

Action	Additional comments or considerations associated with implementation.
1. Support for practice management software	To be compatible with electronic health record to monitor and provide surveillance of tests, medication.
2. MSAC funding of faecal calprotectin testing	Should be combined with 3. If funding is available and systems in place this can be implemented easily. GP guidance/restriction to prevent inappropriate use.
3. Funding of therapeutic drug monitoring	
4. Increased investing, clinical trials and audit of paediatrics	The audits will be an easy place to start, but clinical trials will take longer.
5. Better access to expert advice	
6. Address the challenges of regional centre - hub and spoke relationship?	
7. Explore the potential for effectiveness of medical home – funds bundling.	Can't just be in hospital. Medical model will be different in the Australian context to the USA example.
8. Improve communication pathways for GPs to information/hotlines	
9. Establish clearer GP referral guidelines/protocols	Allow gastroenterologist, surgeon and ND to do referrals. Establish healthcare pathways
10. Improved credentialing and education across all areas of allied health	Train the allied health professional and access will then improve (17)
11. Increasing number of MBS funded visits for allied health + audit of Enhanced care Plan take-up	Should be combined with 17. Could be costly to implement. Currently a lack of trained providers. There is front-end loading, but nutrition falls away. Having specialist access to items.
12. Improve consumer knowledge	Nutrition Psychological health
13. Promote clearer pathways to responsive review for patient both before and after diagnosis	
14. Increased funding for health hotlines for both patient and GP	Connected with and part of the IBD nurses role (23). Ethnic groups
15. Establishing joint IBD and pregnancy clinics	
16. Increase admin support case-worker for IBD clinics	This should be seen as an integral part of an IBD multi-disciplinary team in all hub centres.

17. Greater access to allied health.	Will be achieved by progressing better training for allied health professionals Connection with Centre of Advanced Learning courses in partnership with Dietetics Association of Australia. Allied health model of care should provide opportunities for extended scope of practice.
18. Establish multidisciplinary teams for IBD patients	Necessary for chronic and acute patients, not stable and enable access when necessary. First step is to identify health care professionals involved. Fund allocation is important. This should be achieved in cooperation with increased administrative support for IBD clinics (16) and operate through hubs rather than everywhere.
19. Increase awareness by community services of IBC support groups	
20. Increase connections for specialist language and gender requirements with appropriate specialist and allied health services	
21. Support for development of stomal therapy services in regional Australia	
22. CCA make clear statements about the most appropriate specialists to perform surgeries.	
23. IBD nurses	Easy to implement if funding if available Training in tandem with implementation will shorten the timeframe. Not just public hospitals. Need to be broader, include community and Primary healthcare networks. Consider IBD nurses outreach. Health hotline an important part of success of IBD nurses. Noting the demand for specialist nurses across a range of chronic conditions, and issues regarding general nurse supply, focus may need to be broadened to 'chronic condition nurses' to increase the viability of this recommended action.

Appendix 2 IBD roundtable supporting information

Table 1	Table 2	Table 3	Table 4
<ul style="list-style-type: none"> • General Practice <ul style="list-style-type: none"> ○ Diagnosis – questionnaires; education, clinical insights; FC; quick referral ○ Ongoing – better communication; allied health (specialist); telehealth ○ Enhanced care plans – need more than 5 visits, but from a Government point of view is it not used? • Improved consumer knowledge • Nurses, nutrition (>50% are malnourished), need specialised training, formal course and incentives to specialise. 	<ul style="list-style-type: none"> • Establish state-funded clinical networks • Healthcare homes – pilots (20) being evaluated now • Chronic illness nursing • Voluntary support groups • GP healthline – ethnic groups • Clinical pathways for IBD? • Referrals for mental health services; access mental health planning by gastro specialists. • Telehealth is not necessarily the answer for regional/rural support 	<p><u>Issue</u></p> <ul style="list-style-type: none"> • Lack of communication between appointments leads to deterioration and to hospital. • Outpatient booking delays <p><u>Response</u></p> <ul style="list-style-type: none"> • Go to point in health service for testing of faecal calprotectin • IBD Nurses • Admin support to allow nurses to focus on care. • Nurse follow up e.g. bowel Cancer follow up. • Hotline/helpline • GP review with support of primary health network. IBD gastro specialised support. <p><u>Issue</u></p> <ul style="list-style-type: none"> • Disconnect between inpatient & primary carers <p><u>Response</u></p>	<p><u>IBD Centre (11 on CCA background paper)</u></p> <ul style="list-style-type: none"> • Multidisciplinary clinics; shared care. <p><u>Databases (6&7 clinical & registries)</u></p> <ul style="list-style-type: none"> • Cross-sites clinical data trial in SA and Qld. • Registries • Need for cross-site, changing sites, national • Real time clinical databases for clinical management • Continuity of care for transfer between sites. <p><u>Therapeutic drug monitoring</u></p> <ul style="list-style-type: none"> • Funding required (\$100) • Titrate dose • Integrate with telemonitor <p><u>Hub & spoke – monitoring, trust</u></p> <p><u>Faecal calprotectin testing (8)</u></p> <ul style="list-style-type: none"> • Triaging

<ul style="list-style-type: none"> • Psychological health • Ongoing audit is a priority. • Hub and spoke model involving multi-disciplinary teams <ul style="list-style-type: none"> ○ Agree it is a good idea; interface with telehealth ○ Private/public interface can work, e.g. Sunshine Coast ○ Interested GPs/dieticians could also act as liaisons. • Pharmacy - Care is increasing in complexity, specialised, funding holds in the same way as other allied health. • Emergency care – guidelines; awareness raising of standards; audit 		<ul style="list-style-type: none"> • Surveillance support software • Nurses provide OP hotline responses. <p><u>Issue</u></p> <ul style="list-style-type: none"> • Physician prescribed medication <p><u>Response</u></p> <ul style="list-style-type: none"> • GP contact point for patient – need direct line to hospital managing team <p><u>Issue</u></p> <ul style="list-style-type: none"> • Delay to Diagnostic colonoscopy in public - 6 months waiting <p><u>Response</u></p> <ul style="list-style-type: none"> • PBS faecal calprotectin testing as a diagnostic investigation to help manage colonoscopies. <p><u>Issue:</u></p> <ul style="list-style-type: none"> • Lack of coordinated pregnancy care <p><u>Response:</u></p> <ul style="list-style-type: none"> • Implement/coordinate IBD clinic and pregnancy clinic; joint service. 	<ul style="list-style-type: none"> • Avoiding colonoscopies • MSAC submission – consumer advocacy support • Diagnostic, monitoring, predictive • Use post-op to consider pharm avoid • Funding • Embed into IBD nurse-led clinic • Rural and remote – telehealth and telemonitor.
--	--	---	--

		<p><u>Issue:</u></p> <ul style="list-style-type: none"> • Poor access to psychology and dietetics. <p><u>Response</u></p> <ul style="list-style-type: none"> • Dietitian and psychology access in hospital and community. 	
--	--	---	--