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# Inflammatory Bowel Disease National Action Plan 2018

*A draft document prepared for the  
Australian Government Department of Health*

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- Respondents to the National Stocktake of IBD Improvement Activities Survey
- The various authors of the IBD National Action Plan and related background documents

## ABBREVIATIONS

ACMHN	Australian College of Mental Health Nurses
AIBDA	Australian Inflammatory Bowel Disease Association
AIHW	Australian Institute of Health and Welfare
ANZIBDC	Australia and New Zealand Inflammatory Bowel Disease Consortium
APS	Australian Psychological Society
CCA	Crohn's & Colitis Australia
DAA	Dietitians Association of Australia
EEN	exclusive enteral nutrition
GENCA	Gastroenterological Nurses College of Australia
GP	General Practitioner
IBD	inflammatory bowel disease
IBDNA	IBD Nurses Australia
MBS	Medicare Benefits Schedule
MRFF	Medical Research Future Fund
NSFCC	National Strategic Framework for Chronic Conditions
PBS	Pharmaceutical Benefits Scheme
PCHMs	Patient-centred medical homes
PHN	Primary Healthcare Networks
PSA	Pharmaceutical Society of Australia
PwC	PricewaterhouseCoopers
RACGP	Royal Australian College of General Practitioners
RFDS	Royal Flying Doctor Service
SHPA	Society of Hospital Pharmacists of Australia

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## About this IBD Action Plan

### Vision

*All Australians living with inflammatory bowel disease have access to high quality, integrated care to best manage their own health and improve quality of life.*

IBD is growing in prevalence in Australia and there is increasing evidence that the management of the condition is problematic for individuals and the community as a whole. The opportunity to approach the management of this condition using more effective interventions for chronic disease management is clear. This IBD Action Plan seeks to outline the path to better quality care using solutions developed collectively, that:

- are based on evidence;
- capitalise on examples of excellence in existing care models; and
- align with the National Strategic Framework for Chronic Conditions (NSFCC).<sup>1</sup>

The NSFCC, published in 2016, provides a platform applicable to a broad range of chronic diseases, including IBD, by recognising that there are often similar underlying principles for their prevention and management. In this IBD Action Plan, the NSFCC focus on prevention is prominent and specifically directed at early diagnosis and management of the condition to avoid deterioration and lifelong complications (secondary & tertiary prevention). Equally prominent are actions to provide efficient, effective and appropriate care for those living with this chronic condition. There is a lesser focus on the NSFCC priority population (Aboriginal and Torres Strait Islanders) due to low prevalence of IBD in this cohort.<sup>2,3</sup> The guiding principles of the NSFCC overlap with the World Health Organisation dimensions of quality of care and combined they guide this IBD Action Plan.

The Australian Government announced the development of the IBD National Action plan in April 2018. Crohn's & Colitis Australia (CCA), the peak consumer organisation for people with IBD, has coordinated the consultation process for IBD stakeholders including a national roundtable action planning workshop. Priorities identified at the workshop were further explored by determining the current Australian activities in these areas via a national 'stocktake' survey and detailed literature review (summary documents are available at: *to be inserted in final document*).

Importantly, consumer input to the plan was achieved throughout its development by individual and consumer organisation representation at the roundtable workshop, a concurrent patient experience of healthcare survey by CCA and public comment on the draft IBD Action Plan.

This first IBD National Action Plan is concentrated on implementable actions that can bring tangible benefits to people's individual care and reduce the burden of disease for the community. While cure is ultimately the goal of all stakeholders, this plan provides a path to better care, better quality of life and reduced burden of IBD on the Australian community.

## Purpose

The purpose of this document is to identify the most important short to medium term actions, to improve equitable access to high quality health care for people living with IBD in Australia.

## Why do we need an IBD Action Plan?

IBD is a chronic disease that requires complex long-term care. The trajectory of IBD usually involves periods of remission, flares and relapses. Though it can be diagnosed at any age, it is commonly diagnosed between 15 and 35 years of age and usually has lifelong effects.

There has been a predominantly reactive model of care for acute flares, which is at odds with the recommended proactive approach to management for any chronic condition. <sup>4</sup> PricewaterhouseCoopers (PwC) reported in 2013 that there was an increasing burden of disease for individuals and the nation. They identified two important problems in Australia: increased costs of healthcare utilisation and inadequate and inconsistent care. In 2012, hospital costs attributable to IBD were estimated to be in the order of \$100 million, productivity losses (including loss of earnings, absenteeism and premature death) totalled more than \$361million and other costs associated with taxation revenue impact, carer costs, out-of-pocket expenses, deadweight losses, welfare costs and loss of wellbeing at over \$2.7 billion for the year. In 2018, the burden is expected to be even greater given the increasing prevalence of IBD and the increasing costs in delivering health care services. The report proposed that improvements in the quality of care could alleviate this burden.

A detailed examination of the quality of care was undertaken in 2016 to identify the reasons for variability in care and to measure the quality of care in Australia. <sup>5</sup> Overwhelmingly, it found that care did not meet the levels specified in the Australian IBD Standards 2016 and provided an evidence base for improvement of IBD care. <sup>6</sup> The recommendations of the report also highlighted the shared responsibility to improve care amongst government, planners, healthcare providers and consumers.

Those living with IBD have expressed the problems that limit their ability to participate actively in their own IBD management. High hospitalisation rates, poor access to multidisciplinary chronic disease care, high psychological impact of living with the disease and inadequate responsiveness to deterioration in care are described by patients. <sup>7</sup> There is evidence that developing consumer centred health care that is responsive to the needs and preferences of individuals is associated with a range of positive outcomes for both the individual and the health service system. <sup>8</sup>

Accordingly, for quality improvement plans to be of optimal impact, all stakeholders, including consumers, need to participate in the solution. The Australian Government Department of Health funded the development of this plan which brings together the necessary participants motivated to identify and address the most urgent priorities that will enable improved quality of care for those living with IBD in Australia.

## Action Plan Summary

Priority Area	Action
<b>1. A skilled and accessible multidisciplinary workforce</b>	
<b>1.1 Increased access to specialist IBD nurses</b>	<ul style="list-style-type: none"> <li>a) Implement specialist IBD nurse positions to address demand and increase access in areas of need</li> <li>b) Develop specialist IBD nurse training modules</li> </ul>
<b>1.2 Greater access to multidisciplinary allied health teams</b>	<ul style="list-style-type: none"> <li>a) Implement IBD psychology roles in multidisciplinary teams</li> <li>b) Implement IBD focussed dietitian roles in multidisciplinary teams</li> <li>c) Develop online credentialing courses on IBD management for dietitians, psychologists and pharmacists</li> <li>d) Examine Medicare Benefits Schedule (MBS), General Practitioner (GP) care planning utilisation for referral to allied health clinicians for people with IBD</li> </ul>
<b>1.3 Increase administrative resources to support case-workers in IBD clinics</b>	<ul style="list-style-type: none"> <li>a) Study the cost effectiveness and impact of an administrative role in an IBD team</li> </ul>
<b>2. Access to responsive IBD helplines</b>	<ul style="list-style-type: none"> <li>a) Support for local services to maintain clinically useful helplines</li> <li>b) Implement an IBD helpline network available to support individuals without access to a local helpline</li> <li>c) Conduct an awareness campaign for GPs and primary care providers on the availability of helplines for patients and clinicians</li> </ul>
<b>3. Support general practitioners to more effectively participate in IBD management</b>	<ul style="list-style-type: none"> <li>a) Establish clearer GP referral guidelines and protocols</li> <li>b) Upskill GPs on contemporary IBD management</li> <li>c) Individual action plans for IBD patients</li> </ul>
<b>4. Improved consumer knowledge</b>	<ul style="list-style-type: none"> <li>a) Develop self-management focussed information materials</li> </ul>
<b>5. Increased investing, clinical trials and audit of paediatric care</b>	<ul style="list-style-type: none"> <li>a) Increased investment in research trials for paediatric IBD patients</li> <li>b) Improved/streamlined Pharmaceutical Benefits Scheme (PBS)-subsidised access to new IBD medications for paediatric IBD patients</li> <li>c) Complete a repeat audit of IBD paediatric care to measure change and inform future quality improvement.</li> </ul>

<b>6. Support for practice management software</b>	a) Support for practice management software (IBD specific auditable clinical management software)
	b) Repeat the IBD Quality of Care Audit incorporating data from practice management software
<b>7. Funding of faecal calprotectin testing and therapeutic drug monitoring</b>	a) MBS funding of faecal calprotectin testing (diagnostic indication)
	b) Research funding for health economic analysis of faecal calprotectin testing (monitoring indication) and therapeutic drug monitoring
<b>8. Explore the potential for effectiveness of medical home – funds bundling</b>	a) IBD stakeholders should monitor the evidence produced by the healthcare homes initiative and patient-centred medical homes in the US and identify opportunities for application in Australia

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## IBD in Australia

Crohn's disease and ulcerative colitis are lifelong gastrointestinal disorders that commonly present in adolescence and early adulthood. Collectively known as IBD, the conditions are an established global problem and Australia has among the highest prevalence in the world.

The exact cause of Crohn's disease and ulcerative colitis are unknown. Research evidence shows that genetic, environmental, immunological and infectious (bacterial) factors are involved and it may be their interaction in susceptible people that causes IBD to develop.<sup>9</sup> The prevalence of IBD in Australia is increasing: PwC calculated it to be between 75 302 and 92 571 in 2018. It is estimated to increase to almost 100 000 in 2022 (Table 1).<sup>4</sup>

**Table 1 Projected prevalence of IBD 2013-2022**

	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
<b>Lower</b>	69 215	70 392	71 588	72 805	74 043	75 302	76 582	77 884	79 208	80 475
<b>Upper</b>	85 088	86 535	88 006	89 502	91 024	92 571	94 145	95 745	97 373	99 028

The hallmark of these diseases is inflammation of the gastrointestinal tract (also known as the gut), affecting the colon alone in ulcerative colitis, or anywhere along the gastrointestinal tract in Crohn's disease. The gut becomes red, hot, swollen, tender and does not function normally. This dysfunction can cause a range of problems that include diarrhoea, pain, bleeding, profound fatigue, weight loss, anaemia and bowel obstruction. The disease can become so severe that hospitalisation is required and many people affected by IBD require surgery. The acute symptoms may be extremely distressing and affect an individual's ability to work, study and establish relationships.

Uncontrolled disease often leads to poor health outcomes. All the medications used to treat IBD have potentially severe side-effects and significant associated risks. The chronic relapsing nature of IBD has broader effects on an individual's emotional, physical and social wellbeing. Even when enjoying good health, people with IBD may be concerned about their future, given the unpredictability of its clinical course and the variation in the severity and pattern of disease.

Australian Institute of Health and Welfare (AIHW) data for 2013-14 indicates more than 21 386 admissions to public hospitals for Crohn's disease and ulcerative colitis, 5460 of these were one night or more and the average length of stay was 5.2 days for Crohn's disease and 6.5 for ulcerative colitis.<sup>4</sup>

Though there have been many advancements in treatment over the last decade and pockets of excellence in care, the burden of disease remains high and the quality of care variable and in many cases does not meet the prevailing standard.

## IBD National Action Plan priority areas

The following priority areas have been identified as the most important areas that will impact the improvement of quality of care for people living with IBD. Feedback from the IBD roundtable consultation process has been considered with respect to existing evidence base and the current practices and initiatives identified through the national Stocktake of IBD Improvement Activities. There are many other important areas relating to the management of IBD that could form part of a longer term strategic plan not included in this document, which are noted throughout the supporting evidence publications.

### Priority Area 1: A skilled and accessible multidisciplinary workforce

The highest priority workforce issue identified is the need for accessible specialist IBD nurses for people with IBD. Access to other health professionals in the multidisciplinary team (especially psychologists, dietitians and pharmacists) is also identified as a high priority though the evidence available for implementation warrants a different approach for the various disciplines.

#### 1A Increased access to specialist IBD nurses

Specialist IBD nurses perform a critical role in the provision of high quality IBD care.<sup>10,11</sup> The role provides:

- Timely and responsive access for the patient to allow early intervention and prevention of disease deterioration and subsequent hospitalisation.
- Additional education and support to improve patient adherence and outcomes.
- Improved safety and monitoring of medications and resulting treatment efficacy.
- Relationship to patient which is perceived as more 'equal' than the patient to doctor relationship.

High quality research has demonstrated economic and clinical benefits attributable to the IBD specialist nursing role resulting in reduction in: emergency department presentations, the number of hospital stays, length of stay when admitted and outpatient attendance along with improvement in patient quality of life measurement and satisfaction.<sup>12, 13, 14, 15, 16, 17, 18, 19</sup>

There is limited access to specialist IBD nurses in Australia, largely due to a lack of secure funding for this role. Just 39% of hospitals had some part-time or full-time IBD nurse according to the IBD Audit,<sup>5</sup> meaning that many people with IBD have no access to IBD nurses.

People living with IBD want access to support from IBD nurses.<sup>20</sup> There are a small number of models currently delivering this service with variable reliability of funding.<sup>5, 21</sup> To increase access to IBD nursing and realise the potential benefits to adults and children with IBD and health service efficiency the following priority actions are proposed.

## Priority Area 1A: Increased access to specialist IBD nurses

Action	Detail
<p>a) <b>Implement specialist IBD nurse positions to address demand and increase access in areas of need</b></p>	<ul style="list-style-type: none"> <li>• Implement a minimum of 15 specialist IBD nurse positions in hospital IBD teams nationally over three years. The roles would be incrementally expanded over three years from 5 in year one, to 10 in year two and 15 in year three. The roles will seek to deliver specialised IBD nursing services in areas of demand where they can be effectively supported and provide flexible outreach to areas of need, particularly remote and regional areas</li> <li>• CCA is the lead coordinating body working in collaboration with Gastroenterological Nurses College of Australia (GENCA)/IBD Nurses Australia (IBDNA), Australian Inflammatory Bowel Disease Association (AIBDA) and Royal Flying Doctor Service (RFDS) placement site partners</li> <li>• Appropriate evaluation to examine the impact on hospital demand, quality of care and cost benefit will be undertaken in collaboration with a university.</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Reduced emergency department attendances</li> <li>▪ Reduced unplanned admission rate</li> <li>▪ Improved consumer health literacy</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ Strategic Priority Area (SPA) 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.1 Active engagement</li> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> </ul> </li> </ul>
<p>b) <b>Develop specialist IBD nurse training modules</b></p>	<ul style="list-style-type: none"> <li>• Develop IBD specific education for nurses extending on the existing work and planning to date by GENCA/IBDNA and CCA online platform. Elements of this plan include introductory modules/foundation school, advanced school and development towards a post-graduate course by 2022</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Course enrolments</li> <li>▪ Clinician work setting (public/private/outpatient/inpatient/primary care)</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 2.3 Accessible health services</li> </ul> </li> </ul>

## 1B Greater access to multidisciplinary allied health teams

Allied healthcare professional support underpins chronic disease management and is essential to high quality IBD care. At present multidisciplinary IBD patient care in Australia is variable and insufficient. There is also a lack of evidence to define the optimal levels of allied health provision with dedicated IBD units, such as the size, composition and supporting resources. Nevertheless studies have shown that integrated models of IBD care with good access to allied health improve clinical and psychosocial patient outcomes and are cost effective. <sup>15, 19, 22</sup>

The three allied health professions identified as most required for IBD management are dietitians, psychologists and pharmacists.

We know that mental health comorbidity is high in people living with IBD, but access to psychologists in IBD teams is low. <sup>5, 23</sup> Similarly, dietitians have an essential role in implementing exclusive enteral nutrition (a therapy used to treat active Crohn's disease) and to guide therapeutic diets for IBD complications such as malnutrition, food-associated functional symptoms, risk of bowel obstruction and surgery that requires nutrition optimisation. Again, access to a dietitian in the clinical team is inadequate, despite being a requirement of the standards of care and evidence-based consensus guidelines. <sup>5, 6, 24</sup> With the increasing complexity of IBD drug prescription, administration and therapeutic drug monitoring, specialised pharmacists with expertise in IBD are needed to improve adherence and optimise drug levels. Pharmacist interventions have been shown to improve patient education to increase adherence to IBD maintenance medication. <sup>25, 26</sup>

Priority Area 1B: Greater access to multidisciplinary allied health teams	
Action	Detail
a) Implement IBD psychology roles in multidisciplinary teams	<ul style="list-style-type: none"> <li>• Implement 4, 0.5 EFT pilot IBD psychology roles for 2 years in specialised IBD teams to evaluate optimal resources and outcomes</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Improved psychological screening rates</li> <li>▪ Improved psychological wellbeing (psychometric scores)</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.1 Active engagement</li> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> </ul> </li> </ul>
b) Implement IBD focussed dietitian roles in multidisciplinary teams	<ul style="list-style-type: none"> <li>• Implement 2 pilot IBD dietitian roles in specialised IBD teams to evaluate optimal resources and outcomes as a research study</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Use of exclusive enteral nutrition (EEN)</li> <li>▪ Number of referrals to dietitian</li> <li>▪ Improvement of nutritional status (screening tool)</li> </ul> </li> <li>• <i>Links with NSFCC:</i></li> </ul>

	<ul style="list-style-type: none"> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.1 Active engagement</li> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> </ul>
c) <b>Develop online credentialing courses on IBD management for dietitians, psychologists and pharmacists</b>	<ul style="list-style-type: none"> <li>• Online IBD nutrition course developed by Dietitians Association of Australia (DAA) &amp; CCA</li> <li>• Online IBD mental health course developed by Australian Psychological Society (APS), CCA &amp; Australian College of Mental Health Nurses (ACMHN)</li> <li>• Online IBD pharmacists course developed by Society of Hospital Pharmacists of Australia (SHPA), Pharmaceutical Society of Australia (PSA) &amp; CCA</li> <li>• Targets: <ul style="list-style-type: none"> <li>▪ Course enrolments</li> <li>▪ Clinician work setting (public/private/outpatient/inpatient/primary care)</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 2.3 Accessible health services</li> </ul> </li> </ul>
d) <b>Examine MBS GP care planning utilisation for referral to allied health clinicians for people with IBD</b>	<ul style="list-style-type: none"> <li>• Royal Australian College of General Practitioners (RACGP), CCA and GESA conduct a study of MBS GP management plans to identify uptake of allied health referral in primary care related to IBD need</li> </ul>

### 1C Increase administrative resources to support case-workers in IBD clinics

Administrative duties are required as part of IBD patient care and this has been consistently documented in various studies across multiple countries. The administrative burden of IBD care restricts capacity within clinical roles, which could be directed more productively at patient care, research and teaching. No published evidence was available to demonstrate outcome or cost benefits for the existing level of administration resources compared with the optimal level of support. Logically, allocating administrative work to more suitable staff would create capacity and result in a significant cost reduction and improved quality of service. Administrative support should be factored into each specialist IBD team as a key component to support the multidisciplinary team in delivering quality patient care.

**Priority Area 1C: Increase administrative resources to support case-workers in IBD clinics**

Action	Detail
a) Study the cost effectiveness and impact of an administrative role in an IBD team	<ul style="list-style-type: none"> <li>• Establish an administrative role and study optimal administrative support levels to improve efficiency of IBD services</li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> <li>▪ SPA 2.4 Information sharing</li> <li>▪ SPA 2.5 Supportive systems</li> </ul> </li> </ul>

**Priority Area 2: Access to responsive IBD helplines**

Telephone helplines are useful, cost effective and accepted by the majority of patients in chronic disease management to support self-management.<sup>27</sup> Studies have shown that IBD patients require constant clinical attention as well as non-clinical administrative and logistical information, both of which can be provided rapidly with an IBD helpline.<sup>28</sup> IBD helplines allow timely, responsive disease management approach that enables earlier intervention, timely escalation of management and avoidance of admission.<sup>10, 19, 27, 28, 29</sup> They are highly regarded by patients and there is good evidence that they benefit doctors and the Australian healthcare system by alleviating non-clinical information burden for doctors.<sup>27, 30, 31</sup>

**Priority Area 2 : Access to responsive IBD helplines**

Action	Detail
a) Support for local services to maintain clinically useful helplines	<ul style="list-style-type: none"> <li>• Initiative to develop tools and protocols to support IBD helpline support provided by IBD nurses</li> <li>• Project Officer 6 months</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Suite of helpline tools developed and evaluated</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.1 Active engagement</li> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> <li>▪ 2.5 Supportive systems</li> </ul> </li> </ul>

<p><b>b) Implement an IBD helpline network available to support individuals without access to a local helpline</b></p>	<ul style="list-style-type: none"> <li>• IBD nurse helpline coordinated and provided by a roster of IBD nurses from priority action 1.1a), potentially in collaboration with RFDS</li> <li>• Project officer 6 months</li> <li>• Telecommunications solutions</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Telecommunication solutions identified and implemented</li> <li>▪ IBD helpline roster established</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.1 Active engagement</li> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> <li>▪ SPA 2.5 Supportive systems</li> </ul> </li> </ul>
<p><b>c) Conduct an awareness campaign for GPs and primary care providers on the availability of helplines for patients and clinicians</b></p>	<ul style="list-style-type: none"> <li>• Promotion to GP and rural doctors' access to IBD helpline</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Increased rates of GP/primary care usage of helpline</li> <li>▪ Emergency department presentations avoided</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.1 Active engagement</li> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> <li>▪ SPA 2.5 Supportive systems</li> </ul> </li> </ul>

### Priority Area 3: Support general practitioners to more effectively participate in IBD management

Specialist gastroenterologist care is essential to IBD management. In the Australian setting the role of GP is not only the foundation of healthcare in our community but the pathway to specialist service.<sup>32</sup> GP collaboration in IBD care is very important, particularly in relation to management of concurrent conditions, access to other primary care as well as IBD related monitoring and management.<sup>10</sup> Data suggests that GP IBD knowledge and comfort in IBD management is suboptimal.<sup>33, 34</sup> Other barriers to clear GP referral pathways include: difficulty in diagnosis, lack of clear treatment guidelines and action plans, limited GP adherence to guidelines and poor referral quality.<sup>35, 36, 37, 38</sup>

Primary Healthcare Networks (PHN), are bodies established to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes; and improve coordination of care. PHNs identify priority health areas in plans and though chronic conditions are commonly listed, IBD is not named as a priority for any PHN.<sup>39</sup>

Targeted action is required to support and GPs with the tools to provide better IBD care so that people with IBD have a coordinated treatment team from specialist care through to local primary care.

Priority Area 3: Support General Practice to more effectively participate in IBD management	
Action	Detail
a) Establish clearer GP referral guidelines and protocols	<ul style="list-style-type: none"> <li>• Campaign to promulgate GP/Physician guidelines through AIBDA/RACGP and PHNs utilising existing resources such as Australian Guidelines for General Practitioners and Physicians 2018, IBS4GPs tool and HealthPathways</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ GP awareness of IBD management protocols</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.1 Active engagement</li> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> <li>▪ SPA 2.5 Supportive systems</li> </ul> </li> </ul>
b) Upskill GPs on contemporary IBD management	<ul style="list-style-type: none"> <li>• GESA, RACGP and CCA to deliver a campaign of Continuing Professional Development to GPs</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Improved GP knowledge of IBD management protocols</li> <li>▪ CPD events offered and attended (IBD specific)</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 2.3 Accessible health services</li> <li>▪ SPA 2.5 Supportive systems</li> </ul> </li> </ul>
c) Individual action plans for IBD patients	<ul style="list-style-type: none"> <li>• Personal action plans clarifying communication and actions relating to primary and specialist care teams should be developed for every patient</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Increased rates of consumer reported personal action plan</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.2 Continuity of care</li> <li>▪ SPA 2.3 Accessible health services</li> <li>▪ SPA 2.5 Supportive systems</li> </ul> </li> </ul>

## Priority Area 4: Improved consumer knowledge

Consumer knowledge is important in any complex, chronic disease when patient involvement in their own care is important. This applies to those with IBD, who mostly undertake self-management away from healthcare settings.<sup>40</sup> Therefore good health literacy and consumer knowledge are important for those with IBD. People with IBD often lack complete information about their condition and treatment and want more input into decisions about their care.<sup>20</sup>

Knowledge about the effectiveness of patient education in IBD is limited and inconsistent study methodologies make datasets difficult to compare. Consequently, whilst improved patient knowledge can be demonstrated, positive effects on quality of life and psychosocial outcomes are unproven.<sup>41, 42, 43</sup>

A focus on improving self-management knowledge might be more effective than purely educational programs, though there is certainly a consumer preference for better information.<sup>20</sup>

Priority Area 4: Improved consumer knowledge	
<p>a) Develop self-management focussed information materials</p>	<ul style="list-style-type: none"> <li>• Develop a suite of consumer information resources that are endorsed by CCA, AIBDA and IBDNA and regularly updated for currency of information</li> <li>• Treatment, nutrition, fertility/pregnancy and mental health resources that are IBD focussed are a priority and could extend on the variable existing materials</li> <li>• Develop consumer friendly expectations of care, healthcare communication booklet/e-book</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Suite of self-management focussed information resources distributed</li> <li>▪ Expectations of care booklet distributed</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.3: Critical life stages</li> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.5 Supportive systems</li> <li>▪ SPA 3.2: Action and empowerment</li> </ul> </li> </ul>

## Priority Area 5: Increased investing, clinical trials and audit of paediatric care

There are at least 5000 Australian children with IBD. Optimal management of children with IBD is important to prevent growth failure, prevent lifelong complications and allow normal psychosocial development. <sup>44, 45</sup> There are few choices of medication with a sound evidence base for effectiveness, safety and dosage. <sup>46, 47</sup> There is a need for well-designed and ethical clinical trials in paediatric IBD as a priority, as too many medications are prescribed as 'off label' in children, largely driven by the challenges of paediatric drug trials and delay to paediatric drug approval. Funding is one of the challenges to conducting these clinical trials as well as appropriate trial design to remove barriers to recruitment. <sup>48, 49</sup> It is acknowledged that recruitment of sufficient sample size for clinical trials may be unlikely in Australia and an emphasis on developing therapy with a personalised medicine approach may be more appropriate.

Audit of paediatric care and responsive intervention and reassessment has been demonstrated to improve the quality of care. <sup>50</sup> The Australian IBD Audit 2016 provided a baseline of information to provide evidence for the improvement of paediatric IBD care.

Priority Area 5: Increased investing, clinical trials and audit of paediatric care	
Action	Detail
a) Increased investment in research trials for paediatric IBD patients	<ul style="list-style-type: none"> <li>• Release a targeted call for research into new diagnostic and therapeutic approaches for paediatric IBD patients through the Medical Research Future Fund (MRFF)</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ MRFF call for targeted research</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.3 Critical life stages</li> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.5 Supportive systems</li> <li>▪ SPA 3.2 Action and empowerment</li> </ul> </li> </ul>
b) Improved/streamlined PBS-subsidised access to new IBD medications for paediatric IBD patients	<ul style="list-style-type: none"> <li>• Establish earlier adoption of adult PBS-subsidised medications for paediatric patients in line with practices in the USA and UK</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ PBS listing of medications for paediatric patients</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.3 Critical life stages</li> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.5 Supportive systems</li> <li>▪ SPA 3.2 Action and empowerment</li> </ul> </li> </ul>

<p>c) <b>Complete a repeat audit of IBD paediatric care to measure change and inform future quality improvement</b></p>	<ul style="list-style-type: none"> <li>• Fund multidisciplinary, multi organisational group to complete an audit of the quality of IBD care for children, including survey of the patient and family experience of care</li> <li>• <i>Targets:</i> <ul style="list-style-type: none"> <li>▪ Identify ongoing variation in care for intervention</li> </ul> </li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.3: Critical life stages</li> <li>▪ SPA 2.5 Supportive systems</li> <li>▪ SPA 3.2: Action and empowerment</li> </ul> </li> </ul>
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### Priority Area 6: Support for practice management software (IBD specific auditable clinical management software)

The Australian IBD Standards 2016 and the NSFCC both recognise the importance of capturing clinical data using good information technology systems, sharing data and using it to improve the quality of clinical care for people with chronic conditions. For high quality care, IBD patients require an electronic health record to provide the healthcare team with rapid access to accurate medical records and for regular monitoring of treatment impact, surveillance for serious side effects and other patient management information. <sup>6</sup> Only two in five Australian hospitals audited had an electronic database of clinical information for people with IBD. <sup>5</sup> The Australia and New Zealand Inflammatory Bowel Disease Consortium (ANZIBDC) has recently developed “Crohn’s Colitis Care” (CCCare), an integrated, national, cloud-based, evidence-based, IBD-specific clinical management system capturing real-time clinical data in routine care in Australia (and New Zealand). <sup>51, 52, 53</sup> Early usability and feasibility results (unpublished as of September 2018) show that it is usable and secure. The South Australian government is supporting implementation of this software in hospitals. Other clinical management systems are available and should also be evaluated.

Priority Area 6: Support for practice management software	
Action	Detail
<p>a) <b>Support for practice management software (IBD specific auditable clinical management software)</b></p>	<ul style="list-style-type: none"> <li>• Funding to implement software into new sites with evaluation</li> <li>• Implementation should include paediatric sites to support monitoring paediatric outcomes</li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 2.4 Information sharing</li> </ul> </li> </ul>

<p><b>b) Repeat the IBD Quality of Care Audit incorporating data from practice management software</b></p>	<ul style="list-style-type: none"> <li>• National audit of the quality of care to measure change since the IBD Audit 2016 and inform future quality improvement</li> <li>• Adapt IBD Audit data collection mechanisms to take advantage of existing practice databases to streamline processes</li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 2.5 Supportive systems</li> </ul> </li> </ul>
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## Priority Area 7: Funding of therapeutic drug monitoring and faecal calprotectin testing

Faecal calprotectin testing is effective for identifying gut inflammation and thereby differentiating IBD from the more common condition irritable bowel syndrome. In the IBD clinical management setting it can assist in monitoring relapse and response of current treatment type and as a surrogate marker of mucosal healing or post-operative recurrence.

Recent advancements in IBD treatments include biologic and molecular therapies. Therapeutic drug monitoring is increasingly being used to guide the dosing of these drugs and thiopurine therapies. Recently an expert committee of Australian and international members released a consensus statement recommending therapeutic drug monitoring of anti-TNF agents should be used in various treatment situations.<sup>54</sup> Neither faecal calprotectin testing nor therapeutic drug monitoring attract MBS subsidy and faecal calprotectin testing was recently rejected for MBS listing in August 2018.

<b>Priority Area 7: Funding of faecal calprotectin testing and therapeutic drug monitoring</b>	
<b>Action</b>	<b>Detail</b>
<p><b>a) MBS funding of faecal calprotectin testing (diagnostic indication)</b></p>	<ul style="list-style-type: none"> <li>• Fast track the current faecal calprotectin testing application for the indication of discriminating IBD from non-IBD diagnoses</li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.4 Timely and appropriate detection and intervention</li> <li>▪ SPA 2.3 Accessible health services</li> </ul> </li> </ul>
<p><b>b) Research funding for health economic analysis of faecal calprotectin testing (monitoring indication) and therapeutic drug monitoring</b></p>	<ul style="list-style-type: none"> <li>• Fund research study into health economics of faecal calprotectin testing for the indication of monitoring IBD</li> <li>• Fund research study health economics of therapeutic drug monitoring</li> </ul>

- *Links with NSFCC:*
  - SPA 1.4 Timely and appropriate detection and intervention
  - SPA 2.3 Accessible health services

## Priority Area 8: Explore the potential for effectiveness of medical home – funds bundling.

Patient-centred medical homes (PCHMs), used in primary practice, are intended to centralise primary care needs among a population of patients while decreasing costs and improving the quality of care.

In late 2017, the Australian Government established Health Care Homes around Australia providing care to enrolled patients with chronic conditions. Evaluation of their impact is underway.<sup>55</sup>

Specialised PCMHs are emerging, including 2 IBD PCMHs that have been established in the US which include the specialist for disease specific care.<sup>56</sup>

Though slightly different, the two models show the necessary factors: a team-based approach, a close and integrated payer-provider relationship and the placement of the patient at the centre of the health care universe.<sup>57, 58</sup>

There is early but promising evidence of successes of the 2 IBD PCMHs. To date, results have shown reduced healthcare utilisation (significantly reduced emergency room visits and hospitalisations) and improved patient outcomes resulting from the IBD PCMH model, although only one study has been published thus far.<sup>57, 58, 59</sup>

It is recognised that the evidence for widespread implementation of these models is insufficient at present. Further positive evidence of the impact of these models on chronic disease management would enable the design of a pilot model for the Australian setting.

### Priority Area 8: Explore the potential for effectiveness of medical home – funds bundling.

Action	Detail
a) <b>IBD stakeholders should monitor the evidence produced by the healthcare homes initiative and patient-centred medical homes in the US and identify opportunities for application in Australia</b>	<ul style="list-style-type: none"> <li>• Departments of Health (Federal, State and Territory), GESA and CCA monitor new evidence and explore opportunities for medical patient-centred medical home models in Australia</li> <li>• <i>Links with NSFCC:</i> <ul style="list-style-type: none"> <li>▪ SPA 1.2 Partnerships for health</li> <li>▪ SPA 2.4 Information sharing</li> <li>▪ SPA 2.5 Supportive systems</li> </ul> </li> </ul>

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