

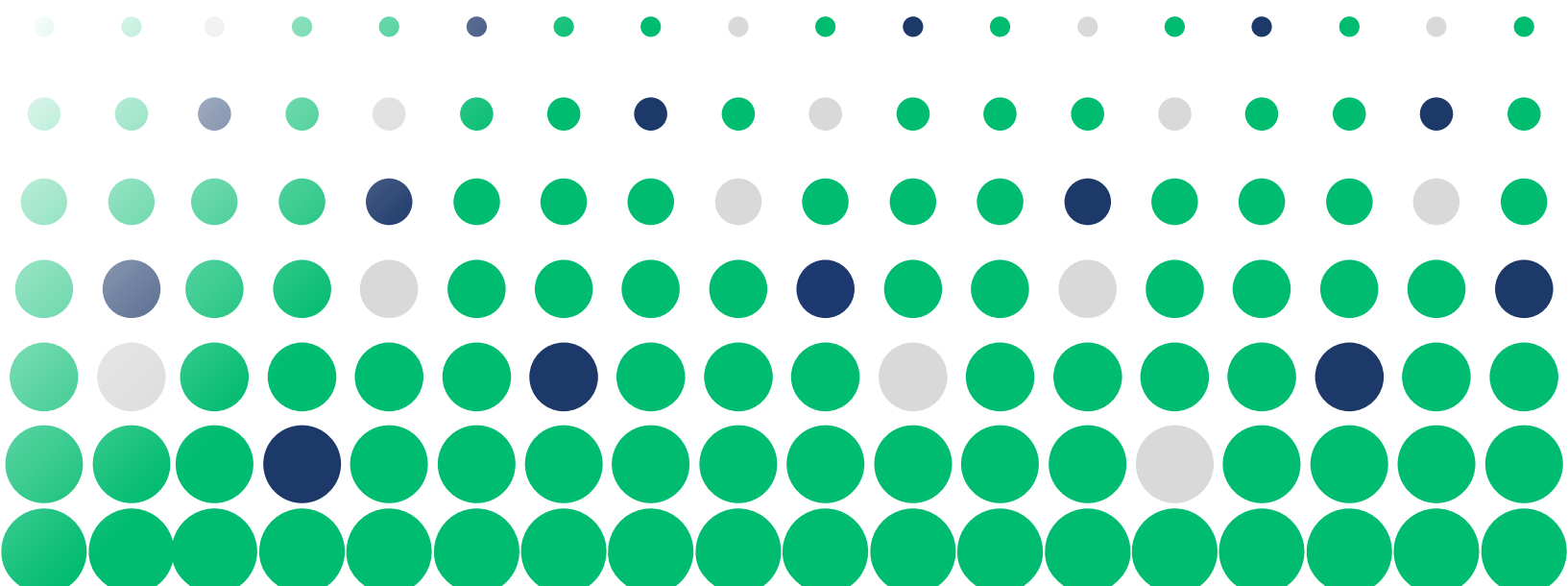


Australian Government

Department of Health

INFLAMMATORY BOWEL DISEASE NATIONAL ACTION PLAN 2019

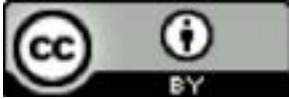
March 2019



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Inflammatory Bowel Disease National Action Plan 2019

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- People living with IBD who have contributed or provided feedback
- Participants in the National IBD Roundtable June 2018 (Appendix A)
- Members of the Scientific, Medical & Quality of Care Advisory Committee, Crohn's & Colitis Australia (Appendix B)
- Respondents to the National Stocktake of IBD Improvement Activities Survey
- The various authors of the IBD National Action Plan and related background documents
- People and organisations that provided feedback on the draft IBD National Action Plan

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
CPD	Continuing professional development
DAA	Dietitians Association of Australia
EEN	Exclusive enteral nutrition
GENCA	Gastroenterological Nurses College of Australia
GESA	Gastroenterological Society 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 NATIONAL 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.

This plan provides detail on the growing prevalence of IBD in Australia and the increasing evidence that 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 National 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).¹

The NSFCC, published in 2017, 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 National 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 population.^{2,3} The guiding principles of the NSFCC overlap with the World Health Organisation dimensions of quality of care and combined they guide this IBD National Action Plan.

The Australian Government announced the development of the IBD National Action plan in April 2018. Crohn's & Colitis Australia (CCA), the peak patient organisation for people with IBD, has coordinated the development of the plan and 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 www.crohnsandcolitis.com.au/ibdqc).

Importantly, input by people living with IBD to the plan was achieved throughout its development by individual and patient organisation representation at the roundtable workshop, a concurrent patient experience of health care survey by CCA and public comment on the draft IBD National 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 that will improve equitable access to high quality health care for people living with IBD in Australia.

WHY DO WE NEED AN IBD NATIONAL ACTION PLAN?

Crohn's disease and ulcerative colitis, known collectively as inflammatory bowel diseases, are chronic diseases that require 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 contradicts the recommended proactive approach to management for any chronic condition.⁴ PricewaterhouseCoopers (PwC) reported in 2013 that there was an increasing burden of disease for individuals and the nation. It identified two important problems in Australia: increased costs of healthcare utilisation and inadequate and inconsistent care. In 2012, PwC estimated that hospital costs attributable to IBD were in the order of \$100 million, productivity losses (including loss of earnings, absenteeism and premature death) totalled more than \$361 million 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 can be expected to be 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 led by CCA in 2016 to identify the reasons for variability in care and to measure the quality of care in Australia, described in the final report of the Inflammatory Bowel Disease Audit 2016.⁵ This national audit examined the resources, organisation and care delivered to people admitted for management of IBD against the Australian IBD Standards 2016.⁶ These consensus standards were produced by a multidisciplinary, multi-organisation committee led by CCA and supported with matched funding from the Australian Government. The standards specify consistent expectations for IBD care for people living with IBD, healthcare professionals, hospitals and IBD stakeholders nationally. Overwhelmingly, the 71 hospitals audited did not meet the levels of care specified in the Australian IBD Standards 2016 and the final report provided an evidence base for improvement of IBD care.⁶ The recommendations of the final report also highlighted the shared responsibility to improve care amongst government, planners, healthcare providers and people living with IBD.

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.⁷ There is evidence that developing patient-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.⁸

Partners

The effective prevention and management of chronic conditions is strongly influenced by the contributions made by a wide range of Partners. These Partners include:

- people with IBD, their carers and families;
- communities;
- all levels of government;
- non-government organisations;
- the public and private health sectors, including all health care providers and private health insurers;
- industry; and
- researchers and academics.



All Partners have shared responsibility for health outcomes according to their role and capacity within the health care system. Greater cooperation between Partners will lead to more successful individual and system outcomes. Actions included in this Action Plan are intended to guide Partner investment in the prevention and management of IBD and should be implemented collaboratively to achieve the best health outcomes.

SUMMARY OF PRIORITY ACTIONS

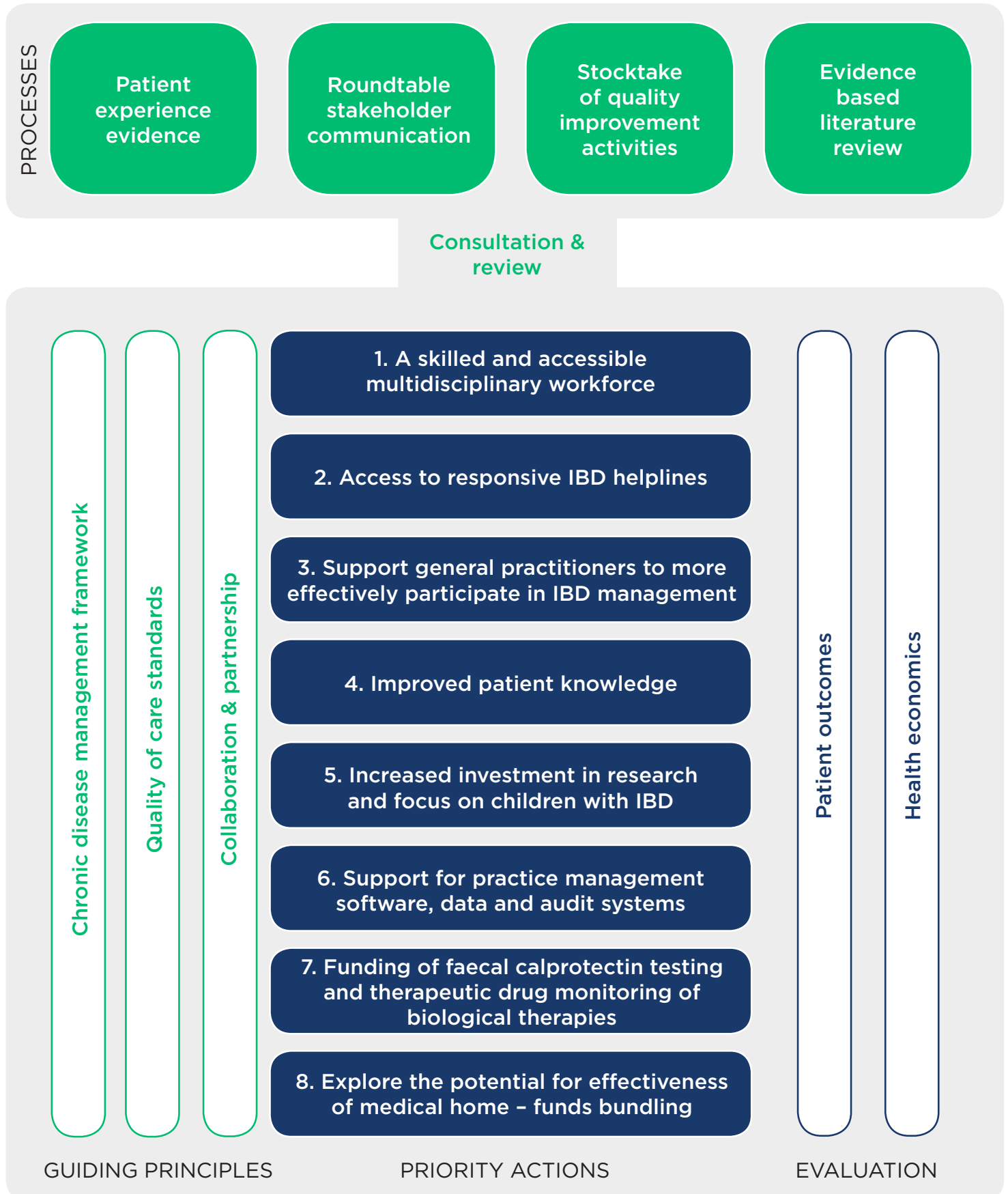
The IBD National Action Plan priority actions are summarised below and described in more detail in this document. A schema of the processes and principles of the plan is provided in **Figure 1**.

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



Figure 1: IBD National Action Plan schema

This schema identifies the processes, principles and evaluation that guide the priority actions outlined within this plan.



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.⁴

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.⁹ The prevalence of IBD in Australia is increasing. PwC calculated it to be between 75 302 and 92 571 in 2018 and is estimated to increase to almost 100 000 in 2022 (Table 1).⁴

Table 1 Projected prevalence of IBD 2013-2022

	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
Lower	69 215	70 392	71 588	72 805	74 043	75 302	76 582	77 884	79 208	80 475
Upper	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 there were 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.⁴ While there is variability in the services available to people in metropolitan areas, specialist IBD services are almost exclusively located in major cities.⁵

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 the existing evidence base and the current practices and initiatives identified through the National Stocktake of IBD Improvement Activities. The priority areas are ordered in accordance with the views of the experts participating in the National IBD Roundtable regarding their level of importance. There are many other important improvements 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. In particular, the various inflammatory bowel diseases are not curable and their management can be burdensome on an individual. Accordingly, research for a cure and treatments with fewer side effects will produce the greatest quality of life improvements in the long-term. To achieve this, there is a need for targeted resourcing of research in adult and child populations in the short term.

Priority Area 1: A skilled and accessible multidisciplinary workforce

Effective chronic disease management requires access to skilled and coordinated multidisciplinary team of health care professionals. The highest priority workforce issue identified through stakeholder consultation is the need for accessible specialist IBD nurses, psychologists, dietitians and pharmacists for people with IBD. The multidisciplinary team should be inclusive and centred on patient need rather than service structures or organisational boundaries. For some people with IBD, other services, such as stomal therapy, physiotherapy, pain management and continence support, are essential to improve health.

Improved access to IBD nurses, psychologists, dietitians and pharmacists will build capacity to support the broader multidisciplinary team including general gastroenterologists, physicians and GPs, particularly those in rural and regional areas where gaps in specialised services exist. The hub and spoke model described in the Australian IBD Standards 2016 provides a framework for access to specialised care in hospital and community, yet there is a need for an expanded workforce and responsive coordinating systems to improve outcomes for patients. The implementation of roles supporting IBD patients should incorporate solutions to improve access and coordination of care for people in rural and regional areas and which results in improved patient outcomes.

Surgery is common for people living with IBD and the delivery of timely, high quality surgical care is crucial. Engagement of surgeons and stoma nurses within the multidisciplinary team in hospital and community is outlined in the Australian IBD Standards 2016.

1.1 Increased access to specialist IBD nurses

Specialist IBD nurses perform a critical role in the provision of high quality IBD care.^{10,11} 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.
- A pivotal role in screening that facilitates referral to the multidisciplinary team.

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.^{12, 13, 14, 15, 16, 17, 18, 19}

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,⁵ meaning that many people with IBD have no access to IBD nurses.

The coordinating role of the IBD nurse has the potential to activate the multidisciplinary team around patients by engaging with the broader team including primary care GPs and allied health members. People living with IBD want access to support from IBD nurses.^{7, 20} There are a small number of models currently delivering this service with variable reliability of funding.^{5, 21} 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 1.1: Increased access to specialist IBD nurses	
Action	Detail
<p>a) Implement specialist IBD nurse positions to address demand and increase access in areas of need</p>	<ul style="list-style-type: none"> • Implement a minimum of 15 specialist IBD nurse positions in hospital IBD teams nationally over three years. The roles would be incrementally expanded over 3 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 in collaboration with GPs and generalist gastroenterologists/physicians. Areas of demand include paediatric and adult care • Appoint a lead coordinating body to work in collaboration with Gastroenterological Nurses College of Australia (GENCA)/IBD Nurses Australia (IBDNA), Australian Inflammatory Bowel Disease Association (AIBDA), Royal Flying Doctor Service (RFDS) and appropriate IBD patient organisation • An appropriate evaluation to examine the impact on hospital demand, quality of care and cost benefit in collaboration with a university • Targets: <ul style="list-style-type: none"> ▪ Reduced emergency department attendances ▪ Reduced unplanned admission rate ▪ Improved consumer health literacy • Links with NSFCC: <ul style="list-style-type: none"> ▪ Strategic Priority Area (SPA) 1.4 Timely and appropriate detection and intervention ▪ SPA 2.1 Active engagement ▪ SPA 2.2 Continuity of care ▪ SPA 2.3 Accessible health services
<p>b) Develop specialist IBD nurse training modules</p>	<ul style="list-style-type: none"> • Develop and deliver 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 • Targets: <ul style="list-style-type: none"> ▪ Course enrolments ▪ Clinician work setting (public/private/outpatient/inpatient/primary care) • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 2.3 Accessible health services



1.2 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.^{15, 19, 22}

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

We know that mental health comorbidity is high in people living with IBD, but access to psychologists in IBD teams is low.^{5, 23} 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 currently inadequate, despite being a requirement of the standards of care and evidence-based consensus guidelines.^{5, 6, 24} 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.^{25, 26}

Priority Area 1.2: Greater access to multidisciplinary allied health teams	
Action	Detail
a) Implement IBD psychology roles in multidisciplinary teams	<ul style="list-style-type: none"> • Implement four 0.5 EFT pilot IBD psychology roles for 2 years in specialised IBD teams to evaluate optimal resources and outcomes as a research study • Targets: <ul style="list-style-type: none"> ▪ Improved psychological screening rates ▪ Demonstrate effective implementation of targeted psychological interventions to improve psychological wellbeing ▪ Improved identification of chronic disease self-management strategies • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.4 Timely and appropriate detection and intervention ▪ SPA 2.1 Active engagement ▪ SPA 2.2 Continuity of care ▪ SPA 2.3 Accessible health services
b) Implement IBD focused dietitian roles in multidisciplinary teams	<ul style="list-style-type: none"> • Implement two pilot IBD dietitian roles in specialised IBD teams to evaluate optimal resources and outcomes as a research study • Targets: <ul style="list-style-type: none"> ▪ Use of exclusive enteral nutrition (EEN) ▪ Number of referrals to dietitian ▪ Improvement of nutritional status (screening tool) • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.4 Timely and appropriate detection and intervention ▪ SPA 2.1 Active engagement ▪ SPA 2.2 Continuity of care ▪ SPA 2.3 Accessible health services

Priority Area 1.2: Greater access to multidisciplinary allied health teams (cont.)	
Action	Detail
c) Implement IBD focussed pharmacist roles in multidisciplinary teams	<ul style="list-style-type: none"> Implement two pilot IBD pharmacist roles in specialised IBD teams to evaluate optimal resources and outcomes as a research study Targets: <ul style="list-style-type: none"> Monitoring and surveillance rates Therapeutic drug monitoring rates and outcomes Detection of adverse events Links with NSFCC: <ul style="list-style-type: none"> SPA 1.4 Timely and appropriate detection and intervention SPA 2.1 Active engagement SPA 2.2 Continuity of care
d) Develop credentialing courses on IBD management for psychologists, dietitians and pharmacists	<ul style="list-style-type: none"> IBD nutrition course developed and delivered in association with Dietitians Association of Australia (DAA) and an appropriate IBD patient organisation IBD mental health course developed and delivered in association with Australian Psychological Society (APS), Australian College of Mental Health Nurses (ACMHN) and an appropriate IBD patient organisation IBD pharmacist course developed and delivered in association with Society of Hospital Pharmacists of Australia (SHPA), Pharmaceutical Society of Australia (PSA) and an appropriate IBD patient organisation Targets: <ul style="list-style-type: none"> Course enrolments Clinician work setting (public/private/outpatient/inpatient/primary care) Links with NSFCC: <ul style="list-style-type: none"> SPA 2.3 Accessible health services
e) Examine MBS GP care planning utilisation for referral to allied health clinicians for people with IBD	<ul style="list-style-type: none"> 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

1.3 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 1.3: 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"> Establish an administrative role and study optimal administrative support levels to improve efficiency of IBD services Links with NSFCC: <ul style="list-style-type: none"> SPA 2.2 Continuity of care SPA 2.3 Accessible health services SPA 2.4 Information sharing SPA 2.5 Supportive systems



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.²⁷ 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.²⁸ IBD helplines allow timely, responsive disease management approach that enables earlier intervention, timely escalation of management and avoidance of admission.^{10, 19, 27, 28, 29} 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.^{27, 30, 31}

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

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.³² 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.¹⁰ Data suggests that GP IBD knowledge and comfort in IBD management is suboptimal.^{33, 34} 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.^{35, 36, 37, 38}

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.³⁹

Targeted action is required to support 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"> • 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 • Targets: <ul style="list-style-type: none"> ▪ GP awareness of IBD management protocols • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.4 Timely and appropriate detection and intervention ▪ SPA 2.1 Active engagement ▪ SPA 2.2 Continuity of care ▪ SPA 2.3 Accessible health services ▪ SPA 2.5 Supportive systems
b) Upskill GPs on contemporary IBD management	<ul style="list-style-type: none"> • GESA, RACGP and CCA to deliver a campaign of Continuing Professional Development to GPs and generalist gastroenterologists / physicians • Targets: <ul style="list-style-type: none"> ▪ Improved GP knowledge of IBD management protocols ▪ CPD events offered and attended (IBD specific) • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 2.3 Accessible health services ▪ SPA 2.5 Supportive systems
c) Develop individual action plans for IBD patients	<ul style="list-style-type: none"> • Personal action plans for deterioration (flare-up) clarifying communication and actions relating to primary and specialist care teams should be developed for every patient • Targets: <ul style="list-style-type: none"> ▪ Increased rates of patient-reported personal action plan • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.4 Timely and appropriate detection and intervention ▪ SPA 2.2 Continuity of care ▪ SPA 2.3 Accessible health services ▪ SPA 2.5 Supportive systems



Priority Area 4: Improved patient knowledge

Patient 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.⁴⁰ Therefore, good health literacy and patient 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.⁷

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.^{41, 42, 43}

A focus on improving self-management knowledge might be more effective than purely educational programs, though there is certainly a patient preference for better information.⁷

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

Priority Area 5: Increased investment in research and focus on children with IBD

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.^{44, 45} There are few choices of medication with a sound evidence base for effectiveness, safety and dosage.^{46, 47} 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.^{48, 49} 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. The lack of paediatric-specific or inclusive clinical trial data in new IBD drugs is placing children with IBD in Australia at a particular disadvantage. While these patients are known to have more aggressive disease, current policy restricts access for children to drugs available to adults.

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

Priority Area 5: Increased investment in research and focus on children with IBD	
Action	Detail
a) Increased investment in research for children and adults with IBD	<ul style="list-style-type: none"> • Release a targeted call for research into new diagnostic and therapeutic approaches for paediatric IBD patients through the Medical Research Future Fund (MRFF) • Release a targeted call for basic/experimental research into IBD through the Medical Research Future Fund (MRFF) • Targets: <ul style="list-style-type: none"> ▪ MRFF call for targeted research • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.3 Critical life stages ▪ SPA 1.4 Timely and appropriate detection and intervention ▪ SPA 2.5 Supportive systems ▪ SPA 3.2 Action and empowerment
b) Improved/streamlined PBS-subsidised access to new IBD medications for paediatric IBD patients	<ul style="list-style-type: none"> • Establish earlier adoption of adult PBS-subsidised medications for paediatric patients in line with practices in the USA and UK • Targets: <ul style="list-style-type: none"> ▪ PBS listing of medications for paediatric patients • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.3 Critical life stages ▪ SPA 1.4 Timely and appropriate detection and intervention ▪ SPA 2.5 Supportive systems ▪ SPA 3.2 Action and empowerment
c) Complete a repeat audit of IBD paediatric care to measure change and inform future quality improvement	<ul style="list-style-type: none"> • 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 • Targets: <ul style="list-style-type: none"> ▪ Identify ongoing variation in care for intervention • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.3: Critical life stages ▪ SPA 2.5 Supportive systems ▪ SPA 3.2: Action and empowerment



Priority Area 6: Support for practice management software, data and audit systems

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.⁶ Only two in five Australian hospitals audited had an electronic database of clinical information for people with IBD.⁵

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),^{51, 52, 53} Early usability and feasibility results (unpublished as of September 2018) show that it is usable and secure. There is further research underway to determine the impact on patient outcomes relating to the quality of referrals to the multidisciplinary team supported by practice management software. 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, data and audit systems	
Action	Detail
a) Support for practice management software (IBD specific auditable clinical management software)	<ul style="list-style-type: none"> • Funding to implement software into more IBD services with evaluation • Implementation should include paediatric sites to support monitoring paediatric outcomes • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 2.4 Information sharing
b) Repeat the IBD Quality of Care Audit incorporating data from practice management software	<ul style="list-style-type: none"> • National audit of the quality of care to measure change since the IBD Audit 2016 and inform future quality improvement • Adapt IBD Audit data collection mechanisms to take advantage of existing practice databases to streamline processes • Specifically resource rural and regional audit and GP/primary care audit to measure prevalence and quality of care • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 2.5 Supportive systems

Priority Area 7: Funding of faecal calprotectin testing and therapeutic drug monitoring of biological therapies

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.⁵⁴

Neither faecal calprotectin testing nor therapeutic drug monitoring of biological therapies attract MBS subsidy and faecal calprotectin testing was recently rejected for MBS listing in August 2018.

Priority Area 7: Funding of faecal calprotectin testing and therapeutic drug monitoring of biological therapies	
Action	Detail
a) MBS funding of faecal calprotectin testing (diagnostic indication)	<ul style="list-style-type: none"> • Continue to progress the current faecal calprotectin testing application for the indication of discriminating IBD from non-IBD diagnoses • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.4 Timely and appropriate detection and intervention ▪ SPA 2.3 Accessible health services
b) Research funding for health economic analysis of faecal calprotectin testing (monitoring indication) and therapeutic drug monitoring of biological therapies	<ul style="list-style-type: none"> • Fund research study into health economics of faecal calprotectin testing for the indication of monitoring IBD • Fund research study health economics of therapeutic drug monitoring • Links with NSFCC: <ul style="list-style-type: none"> ▪ 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.⁵⁵

Specialised PCMHs are emerging, including 2 IBD PCMHs that have been established in the US which include the specialist for disease specific care.⁵⁶ 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.^{57, 58} 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.^{57, 58, 59}

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) IBD stakeholders should monitor the evidence produced by the Health Care Homes initiative and patient-centred medical homes in the US and identify opportunities for application in Australia	<ul style="list-style-type: none"> • Departments of Health (Australian, state and territory), GESA and CCA monitor new evidence and explore opportunities for medical patient - centred medical home models in Australia • Links with NSFCC: <ul style="list-style-type: none"> ▪ SPA 1.2 Partnerships for health ▪ SPA 2.4 Information sharing ▪ SPA 2.5 Supportive systems

REALISING THE VISION

This plan is a step forward in realising the vision of improved quality of life for people living with IBD through high quality integrated care. It provides guidance on the most important areas that will make a difference, driven by the patient experience of care and collaboration, health professional and stakeholder input, evidence base, consultation and review. To achieve effective change, planning is the first important step of a process that requires commitment and ongoing action.

The impact of this plan will be evident through the actions, changes, policies, strategies and services that result. Measuring progress toward the Vision can only be accomplished through assessment of the outcomes experienced by people living with IBD. The process of patient outcome evaluation is essential to every activity in this plan.

Government, planners, health services, industry, clinicians and people with IBD have an opportunity to recognise areas of the plan that match with their future priorities, or appeal to them for innovation, and collaborate to progress actions.

Australian, state and territory governments are significant funders of healthcare. Together with insurers, other payers and people living with IBD, they have a responsibility to be sound stewards of healthcare expenditure. To support this, all actions in this plan should be evaluated for health economic purposes and evidence should be considered with reference to the patient outcomes achieved. The development of this IBD National Action Plan has recognised the current fiscally constrained environment and so should guide the Australian Government and state and territory governments in planning and directing funding in a cost-effective and sustainable way to improve the health of all Australians – specifically, to reduce the incidence and impact of inflammatory bowel disease. Governments will use the activities in this plan to inform their prioritisation of effort. Action will vary in each jurisdiction depending on available resources, current programs and local needs.

The purpose of this document is to identify the most important short to medium term actions that will improve equitable access to high quality health care for people living with IBD in Australia. The implementation of the plan is required to realise improved health outcomes for people living with IBD.



REFERENCES

- ¹ Australian Health Ministers' Advisory Council, "National Strategic Framework for Chronic Conditions," (2017), Australian Government, Canberra.
- ² Day A, Lemberg D & Geary R. Inflammatory Bowel Disease in Australasian Children and Adolescents. *Gastroenterol Res Pract* 2014 Mar 30. doi: [10.1155/2014/703890]
- ³ (abstract) Iyngkaran G, Hunt J, Thambimuthu T et al. Inflammatory Bowel Disease is prevalent in Australia but rare in Indigenous Australians Poster presentation *Epidemiology* 2015 European Crohn's & Colitis Organisation.
- ⁴ PricewaterhouseCoopers Australia (PwC). Improving inflammatory bowel disease care across Australia. March 2013. Available from: <https://www.crohnsandcolitis.com.au/research/studies-reports>
- ⁵ Crohn's & Colitis Australia. Inflammatory Bowel Disease Audit. 2016. Available from: <https://www.crohnsandcolitis.com.au/research/studies-reports/>
- ⁶ Crohn's & Colitis Australia. Australian IBD Standards 2016: Standards of healthcare for people with inflammatory bowel disease in Australia. 2016. Available from: <https://www.crohnsandcolitis.com.au/research/studies-reports/>
- ⁷ Crohn's & Colitis Australia. My IBD Experience. 2018. Available from: <https://www.crohnsandcolitis.com.au/research/studies-reports/>
- ⁸ Australian Commission on Safety and Quality in Health Care. Australian Safety and Quality Goals for health care: Partnering with Consumers. Available from: <https://www.safetyandquality.gov.au/wp-content/uploads/2012/08/3-Partnering-with-consumers.pdf>
- ⁹ Digestive Health Foundation. Inflammatory Bowel Disease (IBD) Crohn's Disease & Ulcerative Colitis. Third edition 2013. Available from: <http://cart.gesa.org.au/membes/files/Consumer%20Information/IBD%20-%20Crohns%20Colitis.pdf>
- ¹⁰ O'Connor M, Bager P, Duncan J, Gaarenstrom J, Younge L, Detre P, et al. N-ECCO consensus statements on the European nursing roles in caring for patients with Crohn's disease or ulcerative colitis. *J Crohns Colitis* 2013;7(9):744-64. Available from: <https://doi.org/10.1016/j.crohns.2013.06.004>
- ¹¹ Inflammatory Bowel Disease Clinical Update 2018, Gastroenterological Society of Australia. Available at: <http://www.gesa.org.au/resources/clinical-guidelines-and-updates/inflammatory-bowel-disease/>
- ¹² Coenen S, Weyts E, Vermeire S, et al. Effects of introduction of an inflammatory bowel disease nurse position on the quality of delivered care. *Eur J Gastroenterol Hepatol*. 2017;29:646-650.
- ¹³ Nightingale A, Middleton W, Middleton S, Hunter J. Evaluation of the effectiveness of a specialist nurse in the management of inflammatory bowel disease (IBD). *Eur J Gastroenterol Hepatol* 2000;12(9):967-73.
- ¹⁴ Andrews, J. How to fund IBD nurses. *JGH Supplement article* 31(2016):43.
- ¹⁵ Phan V-A, van Langenberg DR, Grafton R, Andrews JM. M1037 Introduction of a Dedicated IBD Service Quantitatively and Qualitatively Improves Outcomes in Less Than 18 Months: A Prospective Cohort Study in a Large Metropolitan Centre. *Gastroenterology* 2010; 138: S-318.
- ¹⁶ van Langenberg DR, Simon SB, Holtmann GJ, Andrews JM. The burden of inpatient costs in inflammatory bowel disease and opportunities to optimize care: a single metropolitan Australian center experience. *J Crohn's Colitis*. 2010; 4: 413-21
- ¹⁷ Leach P, De Silva M, Mountfield R, et al. The effect of an inflammatory bowel disease nurse position on service delivery. *J Crohn's Colitis* 2014;8(5):370-4.
- ¹⁸ Bager P. The impact of nurse-led annual telephone follow-up of patients with inflammatory bowel disease. *BMJ Qual Improv Rep* 2014;3(1).
- ¹⁹ Sack C, Phan VA, Grafton R, Holtmann G, van Langenberg DR, Brett K, et al. A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. *J Crohns Colitis* 2012;6(3):302-10.
- ²⁰ Crohn's & Colitis Australia. My IBD Story: co-creating IBD care 2017. Available from: <https://www.crohnsandcolitis.com.au/research/studies-reports/>
- ²¹ Crohn's & Colitis Australia. Stocktake of Inflammatory Bowel Disease Healthcare Improvement Activities Available from: <https://www.crohnsandcolitis.com.au/research/studies-reports/>
- ²² Mikocka-Walus A, Andrews J, Rampton D, Goodhand J, van der Woude J. and Bernstein C. How can we improve models of care in inflammatory bowel disease? An international survey of IBD health professionals. *J Crohns Colitis*. 2014. 8(12): 1668-1674.
- ²³ Mikocka-Walus A, Knowles SR, Keefer L, Graff L. Controversies Revisited: A Systematic Review of the Comorbidity of Depression and Anxiety with Inflammatory Bowel Diseases. *Inflamm Bowel Dis*. 2016 Mar;22(3):752-62 <https://doi.org/10.1097/MIB.0000000000000620>
- ²⁴ Chen J, Andrews J, Kariyawasam V, Moran N, Gounder P, Collins G et al. On behalf of IBD Sydney Organisation and the Australian Inflammatory Bowel Diseases Consensus Working Group. Review article: acute severe ulcerative colitis – evidence-based consensus statements. *Aliment. Pharmacol. Ther.* 2016. July; 44(2): 127-44.

- ²⁵ Ashok K, Anju M, Thomas A, Mohan D, Gopalakrishna R, Reghu, R. Clinical Pharmacist's Interventions on Medication Adherence and Knowledge of Inflammatory Bowel Disease Patients. *J Young Pharm.* 2017. 9(3):381-385
- ²⁶ Tiao D, Chan W, Jegathanan J, Chan J, Perry J, Selinger C et al. Inflammatory Bowel Disease Pharmacist Adherence Counseling Improves Medication Adherence in Crohn's Disease and Ulcerative Colitis, *Inflamm Bowel Dis.* 2017. Aug 1. 23(8):1257-1261, <https://doi.org/10.1097/MIB.0000000000001194>
- ²⁷ Imperatore N, Rispo A, Testa A, Rea M, Nardone OM, Taranto ML, Castiglione, F. Efficacy of a "call center-based communication" in optimizing the care of inflammatory bowel diseases. *Dig Liver Dis.* 2016 Sep 30; 9(48), e114.
- ²⁸ Kemp K, Brooks J, Kirkbride M, Birchall F, Dutton H et al. Cost reductions and in-patient bed days saved by an inflammatory bowel disease nurse helpline. *Gut.* 2017. Supplement 2; London Vol. 66, A235. DOI:10.1136/gutjnl-2017-314472.458 PTH-059
- ²⁹ Patil S and Cross R. Can You Hear Me Now? Frequent Telephone Encounters for Management of Patients With Inflammatory Bowel Disease. *Clin Gastroenterol Hepatol.* 2014. 12(6): 995 - 996
- ³⁰ Stansfield C, Robinson A, Lal S. OC-052 5 year follow up of a nurse led guided self-management programme in ibd. *Gut;* 2015. 64:A27.
- ³¹ Ramos-Rivers C, Regueiro M, Vargas E, Szigethy E, Schoen R, Dunn M, et al. Association Between Telephone Activity and Features of Patients With Inflammatory Bowel Disease. *Clin Gastroenterol Hepatol.* 2014. 12(6): 986 - 994.e1
- ³² Swerissen H, Duckett S and Moran G. 2018. Mapping primary care in Australia. Grattan Institute. Available from : <https://grattan.edu.au/report/mapping-primary-care-in-australia>.
- ³³ Mowat C, Digby J, Strachan J, Wilson R, Carey F, Fraser C, Steele R. Faecal haemoglobin and faecal calprotectin as indicators of bowel disease in patients presenting to primary care with bowel symptoms. *Gut.* 2016. 65:1463-1469.
- ³⁴ Tan M, Holloway RH, Lange K, Andrews JM. General practitioners' knowledge of and attitudes to inflammatory bowel disease. *Intern Med J.* 2012; 42: 801807 [PMID: 21883783 DOI: 10.1111/j.14455994.2011.02586]
- ³⁵ Bennett A, Munkholm P, Andrews J. Tools for primary care management of inflammatory bowel disease: Do they exist? *World J Gastroenterol.* 2015. 21(15): 44574465 Available from: <http://www.wjgnet.com/10079327/full/v21/i15/4457.htm> DOI: <http://dx.doi.org/10.3748/wjg.v21.i15.44577>
- ³⁶ Cabana M, Rand C, Powe N, Wu A, Wilson M, Abboud P-A et al. Why don't Physicians Follow Clinical Practice Guidelines? A Framework for Improvement. *JAMA.* 1999. 282(15):1458- 1467.
- ³⁷ Mathias H, Heisler C, Morrison J, Jones J. A210 The impact of IBD referral quality on wait times. *Can J Gastroenterol Hepatol.* 2018. Mar 1.1(2): 311, <https://doi.org/10.1093/jcag/gwy009.210>
- ³⁸ Jackson D, Con D, Liew D, & De Cruz, P. Clinicians' adherence to international guidelines in the clinical care of adults with inflammatory bowel disease, *Scand J Gastroenterol.* 2017. 52(5); 536-542, DOI: 10.1080/00365521.2017.1278785
- ³⁹ Munro, A (2018). Action Plan - Consultation Contacts for PHNs. [email].
- ⁴⁰ Barlow C, Cooke D, Mulligan K, Beck E, Newman S. A critical review of self-management and educational interventions in inflammatory bowel disease. *Gastroenterol Nurs.* 2010. Jan-Feb;33(1):11-8.
- ⁴¹ Waters B, Jensen L, Fedorak R. Effects of formal education for patients with inflammatory bowel disease: a randomized controlled trial. *Can J Gastroenterol.* 2005. 19: 235-44.
- ⁴² Reusch A, Weiland R, Gerlich C, Dreger K, Derra C, Mainos D, et al. Self-management education for rehabilitation inpatients suffering from inflammatory bowel disease: a cluster-randomized controlled trial, *Health Education Research.* 2016. 31(6): 782-791 <https://doi.org/10.1093/her/cyw042>
- ⁴³ Timmer A, Preiss J, Motschall E, Rücker G, Jantschek G, Moser G. Psychological interventions for treatment of inflammatory bowel disease (review). *Cochrane Libr* 2011;5:1- 132.
- ⁴⁴ Grover Z, Nardi A. and Lewindon P. Inflammatory bowel disease in adolescents. *Australian Family Physician* 2017. 46(8):565-571.
- ⁴⁵ Guariso G & Gasparetto M. Treating children with inflammatory bowel disease: Current and new perspectives. *World Journal of Gastroenterology.* 2017. 3(30): 5469-5485.
- ⁴⁶ Ruellemele F, Hyams J, Otley A, Griffiths A, Kolho, K-L., et al. Outcome measures for clinical trials in paediatric IBD: an evidence-based, expert-driven practical statement paper of the paediatric ECCO committee. *Gut.* 2015. 64: 438-446.
- ⁴⁷ Mulberg A. Off-Label Use of Drugs in Pediatrics: Focus on Pediatric Gastroenterology and Approaches for the Future. *Gastroenterology and Inborn Errors Products (DGIEP)*, United States Food and Drug Administration. 2015. Available at: <https://pdfs.semanticscholar.org/presentation/5295/698b8d190d00973b33644c53bd788e624f4f.pdf>
- ⁴⁸ Turner M, Catapano M, Hirschfield S, Giaquinto C, GRiP (Global Research in Paediatrics). Paediatric drug development: The impact of evolving regulations. *Adv Drug Delivery Reviews.* 2014. 73; 2-13.



- ⁴⁹ Karesh, A, Tomaino J, Mulberg A. Off-label use of medicine in pediatrics: focus on gastrointestinal diseases. *Curr Opin Pediatr*. 2013. 25:612-17.
- ⁵⁰ Fitzgerald M, Mitton S, Protheroe A, Roughton M, Dirscoll R, Arnott D et al. The organisation and structure of inflammatory bowel disease services for children and young people in the UK in 2010: significant progress but still room for improvement. *Frontline Gastroenterol*. 2013. 4:25-31.
- ⁵¹ (abstract) Krishnaprasad K, Walsh A, Begun J, Bell S, Carter D, Grafton R, et al. ANZIBD Consortium, Crohn's Colitis Cure. Crohn's colitis care (CCCare): a bespoke cloud-based clinical management system for inflammatory bowel disease-development and beta testing. *JGH*. 2017. Aug. <https://doi.org/10.1111/jgh.13895>
- ⁵² (abstract) Krishnaprasad K, Walsh A, Begun J, Bell S, Carter D, Grafton R, et al. ANZIBD Consortium, Crohn's Colitis Cure. P328 Crohn's colitis care (CCCare): development and testing of a bespoke cloud-based clinical management system for inflammatory bowel disease (IBD). ECCO (European Crohn's and Colitis Organisation) Poster presentation: Clinical: Diagnosis and Outcome (2018).
- ⁵³ (abstract) Krishnaprasad, Krishnaprasad K, Walsh A, Begun J, Bell S, Carter D, Grafton R, et al. Tu1020 - Crohn's Colitis Care (CCcare) - Development and Testing of a Bespoke Cloud-Based Clinical Management System for Inflammatory Bowel Disease (IBD). *Gastroenterology*, 154(6):S-892. DOI: [https://doi.org/10.1016/S0016-5085\(18\)33012-9](https://doi.org/10.1016/S0016-5085(18)33012-9)
- ⁵⁴ Mitrev N, Vande Castele N, Seow C, Andrews J, Connor S, Moore G, et al. IBD Sydney Organisation and the Inflammatory Bowel Diseases Consensus Working Group. Review article: consensus statements on therapeutic drug monitoring of anti-tumour necrosis factor therapy in inflammatory bowel diseases. *Aliment Pharmacol Ther*. 2017. 46(11-12);1037-53.
- ⁵⁵ Allied Health Services provided to a Health Care Home-enrolled patient. October 2017. Available at: [http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes-cp/\\$File/Allied%20health%20services%20factsheet.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes-cp/$File/Allied%20health%20services%20factsheet.pdf)
- ⁵⁶ Regueiro M, McAnallen S, Greer J, Perkins S, Ramaling S, Szigethy E. The inflammatory bowel disease specialty medical home: a new model of patient-centered care. *Inflamm Bowel Dis*. 2016. 22:1971-1980.
- ⁵⁷ Regueiro M. 2017. Medical Homes for Patients with Inflammatory Bowel Disease. *Gastroenterology & Hepatology* 13(6); 375-377. Available at: <http://www.gastroenterologyandhepatology.net/archives/june-2017/medical-homes-for-patients-with-inflammatory-bowel-disease/>
- ⁵⁸ Regueiro M, Click B, Anderson A, Shrank W, Kogan J, McAnallen S et al. Reduced Unplanned Care and Disease Activity and Increased Quality of Life After Patient Enrollment in an Inflammatory Bowel Disease Medical Home. *Clin Gastroenterol Hepatol*. 2018. S1542-3565(18)30343-4.
- ⁵⁹ Konsinski L. Project Sonar (PS). Advanced Alternative Payment Model. 2016. Dec 21. Available at: <https://aspe.hhs.gov/system/files/pdf/253406/ProjectSonarSonarMD.pdf>

APPENDIX A: PARTICIPANTS IN THE NATIONAL IBD ROUNDTABLE JUNE 2018

Dr George Alex	Royal Children's Hospital Melbourne
Ms Cassandra Anslow	Person with IBD/carer
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/Professor Antonina Mikocka-Walus	Deakin University
A/Professor 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/Professor Leanne Raven	CEO Crohn's & Colitis Australia
Ms Anita Reilly	Person with IBD/carer, 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	Person with IBD/carer



APPENDIX B: MEMBERS OF THE SCIENTIFIC, MEDICAL & QUALITY OF CARE ADVISORY COMMITTEE, CROHN'S & COLITIS AUSTRALIA

A/Professor Gregory Moore	Gastroenterologist (Chair)
Professor Jane M. Andrews	Gastroenterologist
Ms Stephanie Buckton	Nurse Practitioner
Dr Fergus Gardiner	Researcher, Royal Flying Doctor Service
Dr Edward Giles	Paediatric Gastroenterologist
Dr Emma Halmos	Accredited Practicing Dietitian
Dr Simon Knowles	Psychologist
Mr Wayne Massuger	Project Manager, Crohn's & Colitis Australia
Professor Paul Pavli	Gastroenterologist
A/Professor Leanne Raven	CEO, Crohn's & Colitis Australia
Ms Alexandra Sechi	IBD Clinical Nurse Consultant

