

# **Stocktake of Inflammatory Bowel Disease Healthcare Improvement Activities**

A background document for the IBD National Action Plan

October 2018



## Acknowledgements

Crohn's & Colitis Australia (CCA) gratefully acknowledges the healthcare professionals, government departments and their staff for contributing valuable data to this survey. For clinicians, requests such as this add to the busy workload of those dedicated to the care of people living with IBD.

CCA thank the Australian Government Department of Health for providing funding to conduct this work as part of the broader IBD National Action Plan grant.

## About CCA

Crohn's & Colitis Australia (CCA) is a not-for-profit organisation that supports 85 000 people living with Crohn's disease and ulcerative colitis. Established in 1985 the organisation delivers support programs such as education, advocacy, counselling, increasing awareness, and generating and utilising funds for research and support. CCA, the peak national group representing people with inflammatory bowel disease (IBD), engages with the key stakeholders in IBD care and services including its members, others living with IBD, medical and healthcare professionals and their representative bodies, hospitals, primary health, State and Commonwealth governments, industry groups and the broader health advocacy sector. Visit [www.crohnsandcolitis.com.au](http://www.crohnsandcolitis.com.au) for more information about this report or CCA's programs and services.

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## Purpose

This document aims to provide background information for the development of the Inflammatory Bowel Disease (IBD) National Action Plan 2018. It is a summary of the information provided by government and health care sector representatives on the current activities (mid 2018) to improve the quality of IBD care in Australia. This document, together with the IBD National Action Plan Literature Review and IBD Roundtable Report provide a comprehensive suite of background evidence which inform the IBD National Action Plan 2018.

Crohn's & Colitis Australia (CCA) are developing an Inflammatory Bowel Disease (IBD) National Action Plan for the Australian Government Department of Health. The aim of the plan is to identify key goals for the improvement of the quality of care for people living with IBD and specify priority actions to achieve these goals. In order to identify high quality practices and models of care, as well as gaps in service provision, CCA undertook a national stocktake by survey of current improvement initiatives.

## Method

CCA undertook a simple text data collection via an online survey to Federal and State Governments, health professional representative bodies and health care clinicians.

The survey questions sought to identify any activity, present or imminently pending, intended to improve the quality of care for people living with IBD (including Crohn's disease, ulcerative colitis, indeterminate colitis and microscopic colitis). The survey was not limited in type of activity, but possible topic areas relating to the priorities identified at the IBD National Roundtable in June 2018 were listed:

- Increased access to specialist IBD nurses
- Health hotlines for both patient and GP
- Increase administrative resources to support case-workers in IBD clinics
- Greater access to allied health in hospital or via MBS funded visits as part of chronic disease care plans
- Funding of therapeutic drug monitoring , including funding of faecal calprotectin testing
- Establish clearer GP referral guidelines and protocols
- Improved consumer knowledge
- Multi-disciplinary teams for IBD patients
- Improved credentialing and education across all areas of allied health

- Support for practice management software
- Increased investing, clinical trials and audit of paediatrics
- Healthcare homes - effectiveness of funds bundling

Invitees to participate in the survey included Federal and State Health Department heads, chief clinical roles, professional bodies involved in IBD care, gastroenterologists and IBD nurses (see **Appendix 1** for a complete list). Reminders were sent to invitees, but it should be acknowledged that invitees could not be compelled to contribute.

Activities that related to projects testing new molecules/treatment were excluded to keep contributions focused on quality of care activities and research.

Activities reported were grouped according to a condensed set of 10 priority areas and an 'other' category as described in the Reported Activities section.

## Reported Activities

The survey collected information on 77 reported activities from 20 respondents. A further 5 respondents indicated that there were no improvement activities to report in their jurisdiction or site. Responses were not received from WA or ACT.

Activities reported through the survey are summarised according to 10 priority areas and are shown in full in the table for each priority.

### 1. Increased access to specialist IBD nurses

IBD nurse services were reported five times. Most are described as “unfunded” or have inadequate limited funding. One site reported two securely funded positions. Functions and benefits of the role described include: first contact point (helpline), clinic role, staff education, coordination of admissions and appointments, and infusion support. One site reported cost savings through prevention of ED presentations as a result.

There are no postgraduate IBD specific nursing courses. Some education opportunities have commenced and there is planning for extension of the program, though no funding is identified.

**Table 1 Increased access to specialist IBD nurses**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
RCH Melbourne	Increase awareness of the role of Paediatric IBD nurses	To improve care provision to IBD patients through the use of the IBD nurse	Remains an unfunded position but continuing to develop the role within boundaries of allocated time and sessions. Promoting the nurse as the frontline first port of call and contact
Liverpool Hospital	CHEAP	Implementation of nurse led IBD Helpline and Virtual Clinic at Liverpool Hospital	We have demonstrated over \$700K cost savings through prevention of presentations to ED and to the clinic through implementation of the Helpline and Virtual Clinic

<p><b>Lyell Mc Ewin Hospital, Northern Adelaide LHN</b></p>	<p>IBD nurse cover from endoscopy nurse funding – 0.3 session to cover IBD clinic and administration of appointments, coordinating infusions and assisting with biologic application/ monitoring.</p>	<p>Provide some access to IBD nurse care (current position held by a Level 1 nurse)</p>	<p>Better patient communication with IBD service allowing optimisation of the IBD service. Need more funding to provide full access to IBD nurse services.</p>
<p><b>Royal Adelaide Hospital /Central Adelaide Local Health Network</b></p>	<p>Increased access to specialist IBD nurses</p>		<p>We have 2.0 Full Time Equivalent (FTE) IBD nurse support within the Royal Adelaide Hospital (RAH) – this is on secure (regular) funding.</p>
<p><b>Southern Adelaide Local Health Network (SALHN)</b></p>	<p>Access to specialist IBD nurses and IBD hotline service</p>	<p>Allow patients access to an IBD hotline, disease education, coordination of inpatient and outpatient care, safety monitoring for immunomodulators, rapid and early treatment for active disease by phone, and biological access via facilitation of script paperwork.</p>	<p>The effectiveness of this service is threatened by a lack of resources. Despite a fourfold increase in the number of patients prescribed biologic therapy over the past 8 years (where most nursing resources are required) our permanent nursing FTE funded by the hospital has not increased. This has unfortunately resulted in a threat to hotline services to patients, as nursing time is increasingly spent ensuring biologic drug access and coordinating blood monitoring for immunomodulator safety. We collated data suggesting that our hotline service receives 8-10 calls per day from patients, and prevents at least 1 ED presentation per day.</p>
<p><b>CCA</b></p>	<p>CCA IBD Quality of Care - Patient Experience Survey</p>	<p>Assess quality of care from consumer perspective, including IBD Nurse data</p>	<p>Various aspects of the quality of care relating to IBD nurse will be described (report pending)</p>
<p><b>IBDNA</b></p>	<p>IBD nurse education</p>	<p>Develop IBD specific structured education opportunities to extend the knowledge and skills of nurse working with IBD patients</p>	<p>IBDNA plan to provide structured on line and face to face training opportunities for nurses new to IBD nursing via GENCA and IBDNA web platform commencing 2019. We have developed an in-depth education plan.</p>

Three introductory on line Modules have already developed by international IBD Nurse Group. These can be accessed via GENCA and / or CCA web platforms and are aimed at nurses with < 24 months IBD nurse experience. The modules are currently funding by sponsor and are not secure into the future. A further 2 modules are in development for nurses with more IBD experience and will follow on from the first 3 introductory modules. There is no funding identified for this or any further education described hereafter.

Annual IBD Nurse Foundation School currently in development to run annually alongside GENCA National Conference. A volunteer group of IBD nurses are developing the program.

Alternate years the IBD Nurse Advanced School will run alongside AGW for nurses who have completed the 5 modules and if < 2 years IBD nurse experience they must also have attended the foundation school. This is aimed at preparing experienced IBD nurses with advanced practice skills. We have already run 2 of these through GENCA.

We are also developing a mentorship program to support newer IBD nurses by buddying with a senior IBD nurse and there are plans to have a GENCA IBD Nurse credentialing process in line with the endoscopy nurse credentialing that GENCA have supported for a number of years.

			Future plans to work with academic institutions to develop a post graduate IBD nursing course by 2022 would be good to flesh out and add to the NAP.
<b>Women's and Children's Health Network (W&amp;CHN) SA</b>	Increased access to specialist IBD nurses	<b>Comment</b> We do not have a dedicated IBD nurse. Nurse does this as part of the overall role as gastroenterology nurse practitioner incorporating all gastroenterology and home parenteral nutrition. However, Nurse is planning on investigating what patients/families might want from a nurse led clinic for young people with IBD. This project will be starting later this year and Nurse hopes to develop a model of care for a nurse led clinic.	

## 2. IBD helplines responsiveness to patients and GPs

IBD Helplines were reported by three sites as well as a fourth site an informal non-dedicated service. IBD helplines were responsible for avoidance of emergency department visits at two sites, and also provided education, coordination of appointments, rapid early treatment and safety monitoring. Uncertain or absent funding was a problem for the few sites that reported services.

**Table 2. Helplines**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
<b>Susan Connor</b>	CHEAP	Implementation of nurse led IBD Helpline and Virtual Clinic at Liverpool Hospital	We have demonstrated over \$700K cost savings through prevention of presentations to ED and to the clinic through implementation of the Helpline and Virtual Clinic
<b>Royal Adelaide Hospital /Central Adelaide Local Health Network</b>	Health hotlines for both patient and GP		Yes, we have a help-line and an email advice service – would not be possible without our IBD nursing staff.



<b>Southern Adelaide Local Health Network (SALHN)</b>	Access to specialist IBD nurses and IBD hotline service	Allow patients access to an IBD hotline, disease education, coordination of inpatient and outpatient care, safety monitoring for immunomodulators, rapid and early treatment for active disease by phone, and biological access via facilitation of script paperwork.	<p>The effectiveness of this service is threatened by a lack of resources. Despite a fourfold increase in the number of patients prescribed biologic therapy over the past 8 years (where most nursing resources are required) our permanent nursing FTE funded by the hospital has not increased.</p> <p>This has unfortunately resulted in a threat to hotline services to patients, as nursing time is increasingly spent ensuring biologic drug access and coordinating blood monitoring for immunomodulator safety.</p> <p>We collated data suggesting that our hotline service receives 8-10 calls per day from patients, and prevents at least 1 ED presentation per day.</p>
<b>CCA</b>	CCA IBD Quality of Care - Patient Experience	Assess quality of care from consumer perspective	Various aspects of the information provision and responsiveness will be described (report pending)
<b>Women's and Children's Health Network (W&amp;CHN) SA</b>	Health hotlines for both patient and GP	<p><b>Comment</b></p> <p>Not a dedicated hotline but patients and families contact nurse via phone or doctors through the GE department.</p>	

### 3. Increased administrative resources to support case-workers in IBD clinics

Administrative resources to assist clinicians with the care of patients with IBD were reported at two sites but neither had health system funding and one site has ceased the position. Administrative support is described as supporting with data entry, paperwork burden (both essential to quality improvement processes) and appointment reminders which result in improved clinic efficiency.

**Table 3. Administrative resources**

Organisation name	Name of activity	Description of activity and outcomes
Royal Adelaide Hospital /Central Adelaide Local Health Network	Increase administrative resources to support case-workers	In IBD clinics for last 18 months we now employ a 0.5 FTE administrative support officer out of funds we raise from participation in commercial sponsored trails (usually IBD-related drugs). Paperwork burden was unmanageable without this position – but told no funding from within directorate for it.
Southern Adelaide Local Health Network (SALHN)	Administrative resources and support for clinical management software	Up until 2 years ago our IBD service had access to 0.5FTE admin assistant using “soft money”. This funding was lost and as a result our data base has not been updated since this service ceased. This makes it difficult to provide an overview of the patients under SALHN IBD care. Additionally, the new clinical management software developed by the CCC with the aim of improving patient care will not be possible to use at SALHN without administrative support to assist in data migration. This software, with its inherent transparency and standardisation of clinical management, is likely to improve patient care, and would be beneficial to introduce. Administration support would also assist in sending patients SMS reminders to attend clinic, resulting in fewer missed appointments, and thus better care (we note an increase in missed appts since the loss of our admin officer).

#### **4. Greater access to multidisciplinary allied health care teams in hospital, including increasing the number of MBS funded visits for allied health (primary care) and improved credentialing and education across all areas of allied health**

A variety of activities involving the multidisciplinary team were reported in hospitals and outpatient settings.

Several sites reported having multidisciplinary teams including nurses, dietitians and psychologists. A couple conducted regular multidisciplinary team meeting to discuss cases, involving allied health, medical and surgical team members.

A number of alternative clinics were reported to reduce demand on public outpatient areas:

- private multidisciplinary clinic
- psychology service
- intestinal ultrasound in collaboration with dietitian advice to manage functional conditions and reduce demand on clinics, CT and MRI.
- optimal care pathway to using exclusive enteral nutrition
- dietitian clinics

Multidisciplinary or allied health services to support specific issues were identified:

- a pharmacist led thiopurine monitoring service has been introduced to monitor and manage adverse effects after commencing thiopurine therapy and to provide education to improve compliance with IBD medications.
- deliver intensified biologic therapy to IBD patients with incomplete response or secondary loss of response
- transitional care for young adults

Limited access to allied health such as dietitians and psychologists was reported. Though a number of innovative models are described here, they are not accessible throughout the nation.

A free online information and focused psychological intervention for anxiety and or depression associated with IBD is currently operating in addition to some clinic psychology services.

**Table 4. Multidisciplinary care**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
Concord Hospital NSW	IBD Clinic, IBD Transition Service	Multidisciplinary and transitional care	Our current IBD Clinic provides multidisciplinary care incorporating IBD dietitian and a psychologist. We receive public and private patients transitioning from Westmead Childrens Hospital.
Concord Hospital NSW	Macquarie University Hospital	Privately insured patients who are well on a stable management plans can be seen privately to reduce the waiting list at Concord Hospital	Privately insured patients who are well and on a stable management plans can be seen privately to reduce the waiting list at Concord Hospital. An IBD nurse and IBD fellow are present to support the care of IBD patients and an infusion service is provided for those on biological agents or Janssen Live program.
Monash Health	Pharmacist led thiopurine monitoring service	To provide monitoring and management of adverse effects after commencing thiopurine therapy and to provide education to improve compliance with IBD medications.	An IBD pharmacist discusses the new treatment with patients then performs at least two reviews of the patient to detect adverse effects on blood monitoring or self-reported effects. These reviews can be conducted by telephone which is more convenient for patients. The pharmacist manages side effects where possible and reviews thiopurine metabolites test results, making adjustments to therapy in collaboration with a gastroenterologist. It is hoped the service will improve patient adherence, provide more consistent detection of adverse effects and reduces gastroenterologist workload, allowing time to provide more complex care.
QLD Health, Redcliffe Hospital	Commencement of Psychology Outpatient Service	Provide follow-up outpatient psychology care to IBD patients and reduce the cost to the hospital of re-admissions and ED presentations.	Very early stages, not yet providing a service. Collecting some initial data and input from gastro regarding how many referrals can be expected per year and likely provide a small initial trial service.
Redcliffe Hospital	Gastroenterology Dietitian Clinic	Improve access to dietetic care for patients with IBD	With increase in gastroenterology services at Redcliffe Hospital a GE dietitian clinic was created. This has improved local access to dietetic services for our IBD patients.

CCA	CCA IBD Quality of Care - Patient Experience	Assess quality of care from consumer perspective	Various aspects of the access to multidisciplinary care will be described (report pending)
RCH Melbourne	Ongoing development of the multi D team	To improve participation with input from Psychology	Currently running a meeting every 2 weeks with presence of Gastroenterologist, Surgeons, Dietician, IBD nurse, fellows and Pharmacist
Queensland Health	Development of an intestinal ultrasound service for Royal Brisbane and Women's Hospital, Metro North Hospital and Health Service	Introduce a highly accurate point of care test to reduce the demand on colonoscopy, MR and CT for young people with functional GI disorders and those with inflammatory bowel disease	In collaboration with Allied health (dietitians), we propose an alternate model where patients who have functional bowel symptoms are assigned to an assessment with intestinal ultrasound (provided by gastroenterologists) and dietary advice provided by a dietician. We would compare the diagnostic accuracy and patient satisfaction of the ultrasound guided assessment against the "usual care pathway" over a 12 month period. It is anticipated that this will significantly reduce the numbers of patients in this cohort undergoing colonoscopy, and as the service is provided along with a consultation (point of care model), reduce the requirement for follow up clinical consultation, therefore reducing the waiting list for both colonoscopy and for outpatient consultation.
CSSANZ	MDM meetings at St. Vincent's Melbourne & Eastern Health Melbourne	Improve care of IBD patients	Active weekly case discussion & management plans
The Alfred	Virtual Clinic	To deliver intensified biologic therapy to patients with IBD with incomplete response or secondary loss of response	We have been running this clinic monthly at our hospital (Alfred) for nearly 3 years. It is a novel model of care to deliver consistent, high quality care.
Monash Children's Hospital	Establishment of young adult IBD clinic	Improve outcomes for young people including during transition	Establishment of clinic with joint paediatric and adult IBD specialists. Survey of patients and prospective audit of Accident & Emergency attendance/admissions.

<b>Australian Society of Parenteral &amp; Enteral Nutrition</b>	AusPEN Exclusive Enteral Nutrition in Crohn's Disease Project	To develop an Optimal Care Pathway to using exclusive enteral nutrition and reintroduction of diet in adults with Crohn's Disease.	AusPEN is partnering with Dietitian Crohn's Colitis Australian Network (DECCAN) to develop a position statement and clinical practice toolkit for use of Exclusive Enteral Nutrition in Adults with Crohn's Disease.
<b>Logan Hospital</b>	Exclusive enteral nutrition (EEN) adherence in adult patients with small bowel Crohn's disease	To ascertain if providing regular specialist dietetic support (minimum of weekly face to face or telephone review) results in >80% of adult patients with SB CDx adhering to an EEN protocol	This is a single site study I'm carrying out to examining a specific cohort of adult patients, over the age of 18years at Logan hospital. These patients are outpatients with small bowel Crohn's disease referred from an IBD Specialist clinic for a trial of EEN at Logan hospital. I'm just submitted a study protocol for ethics approval.
<b>Queensland Health</b>	Dietitian First Gastro Clinics - Extended Scope of Practice models of care	I developed and ran the first DFGC in Bundaberg in 2013/14 <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5073884/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5073884/</a> & <a href="https://onlinelibrary.wiley.com/doi/abs/10.1111/1747-0080.12283">https://onlinelibrary.wiley.com/doi/abs/10.1111/1747-0080.12283</a>	The focus of the current study was a dietitian-led gastroenterology clinic operating under an extended scope of practice model at a tertiary hospital in regional Queensland, Australia. Gastrointestinal (GI) disease states commonly involve medical nutrition therapy from a dietitian. However, in this case, the dietitian acted as the first practitioner of contact; triaging patients to tests and providing nutritional advice where appropriate. Patients who could not be managed exclusively by the dietitian progressed to a consultation with the gastroenterologist.
<b>Swinburne University of Technology</b>	IBDclinic.org.au	Provide psychoeducation and focused free online psychological intervention for anxiety and or depression associated with IBD see <a href="http://www.IBDclinic.org.au">www.IBDclinic.org.au</a>	Free online information and focused psychological intervention for anxiety and or depression associated with IBD
<b>RMH and The Alfred</b>	Links with psychologist to multi-disciplinary teams for IBD patients	Improve patient outcomes	Honorary positions at various hospitals to provide help/advice.
<b>MindOverGut psychological services</b>	Access to allied health in hospital	Provide psychological service for IBD patients	Provide bulk-billed psychological service at RMH for IBD patients

Lyell Mc Ewin Hospital, Northern Adelaide LHN	Setting up a Joint IBD clinic with Consultant colorectal surgeon once a month – colorectal surgeon committing own time to this service.	Streamlining IBD patients into a specialised IBD/Surgical clinic where clinical management is optimised and decrease issues with overall duplication of appointments.	Decrease in delay to review IBD patients requiring surgical consult, decrease in delay to review IBD patients in surgical clinics and allows joint decisions to be made between gastroenterologist, surgeon and patient.
Lyell Mc Ewin Hospital, Northern Adelaide LHN	IBD Multidisciplinary Team (MDT) meeting once a month – set up jointly with colorectal surgery and radiology to discuss complex IBD patients.	Provide an MDT forum to discuss management of complex IBD patients	Better overall management of complex IBD patients.
Royal Adelaide Hospital /Central Adelaide Local Health Network	Multi-disciplinary teams for IBD patients		<p>We have good IBD nursing support. Dietetics department are supportive but under-resourced and cannot participate as optimal. Colorectal surgeons at RAH provide excellent support and engagement – co-publication in research and meet more than weekly. Radiology also provides excellent support. We have inadequate administrative support (via soft funding only) and the Psychology staff is insecure at present (at risk). We have 2 FTE of clinical trials coordinators who self-fund and also earn enough to cover some administrative time.</p> <p>We hold a fortnightly IBD Multidisciplinary Team (MDT) meeting with nursing, colorectal, radiology, psychological &amp; dietetic representation.</p>
Royal Adelaide Hospital /Central Adelaide Local Health Network	Greater access to allied health in hospital or via MBS funded visits as part of chronic disease care plans	<p><b>Comment</b></p> <p>We have very poor access to dietitians for our IBD outpatients. Each new IBD patient and all people with active disease should have dietetics review, however we were recently asked by the dietitians to stop referring each new patient as they do not have sufficient staff to manage this. They are now also increasingly unable to meet the inpatient IBD assessment demand. We have no access to secure funded mental health support for our IBD patients at present. We have funded (from research money) a 0.5 FTE Psychologist for the last 3 years from research grant funding and now have data showing improvements in mental health outcomes, drug adherence</p>	

and reduced Emergency Department (ED) visits when people are offered psychological screening and targeted Psychology support when warranted. On this basis we have made an application to gain ongoing funding for this role as the demonstrated savings (ED visits and IBD Nurse calls avoided) exceed the annual salary cost. At present this staff member is being supported by funds I earn after hours via lectures, Advisory Boards etc.

### **5. Funding of therapeutic drug monitoring including faecal calprotectin testing**

Though there is no current MBS funding for IBD therapeutic drug monitoring of faecal calprotectin testing some sites have found mechanisms or are supported to conduct these tests.

Consensus Statements on Therapeutic Drug Monitoring have been published to guide practice in this area. Biologic agent level testing is provided through Liverpool hospital. It was reported that two paediatric hospitals and the SA government are funding therapeutic drug monitoring and faecal calprotectin testing.

As mentioned previously a pharmacist led service to monitor and manage Thiopurine has been established.



**Table 5. Therapeutic drug monitoring and faecal calprotectin testing**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
Concord Hospital NSW / GESA	Australian IBD Consensus Working Group	Each one focuses on a field within IBD that is rapidly changing and allows the development of guidelines and auditable data.	This group of Australian and international gastroenterologists and other specialists have completed to date 2 consensus meeting both published in a leading gastroenterology specialty journal Alimentary Pharmacology and Therapeutics. Each one focuses on a field within IBD that is rapidly changing and allows the development of guidelines and auditable data. In 2015 we published the Consensus Statements on Acute Severe Ulcerative Colitis and in 2017 we published Consensus Statements on Therapeutic Drug Monitoring.
Monash Health	Pharmacist led thiopurine monitoring service	To provide monitoring and management of adverse effects after commencing thiopurine therapy and to provide education to improve compliance with IBD medications.	An IBD pharmacist discusses the new treatment with patients then performs at least two reviews of the patient to detect adverse effects on blood monitoring or self-reported effects. These reviews can be conducted by telephone which is more convenient for patients. The pharmacist manages side effects where possible and reviews thiopurine metabolites test results, making adjustments to therapy in collaboration with a gastroenterologist. It is hoped the service will improve patient adherence, provide more consistent detection of adverse effects and reduces gastroenterologist workload, allowing time to provide more complex care.
RCH Melbourne	Funded therapeutic drug monitoring of thiopurines, TNF and also calprotectin for test done within the hospital	To continue to lobby funding via GESA and MSAC of these test to be covered when done privately	Better access of these test beyond the hospital setting

Liverpool Hospital	Biologic level testing service at Liverpool Hospital	To enable clinicians in Australia to use biologic level testing to ensure optimised biologic dosing of IBD patients	The Consensus on Therapeutic Drug monitoring published in APT is on GESA website
Royal Adelaide Hospital /Central Adelaide Local Health Network	Funding of therapeutic drug monitoring, including funding of faecal calprotectin testing		SA Health is covering the cost of faecal calprotectin testing – which enables better non-invasive monitoring of disease activity. Drug levels for: Infliximab are available via pharmaceutical company funding and are performed in New South Wales (NSW) at Liverpool hospital. SA Health covers costs of sample transport. Thiopurines are done via SA Pathology and well used and appreciated Adalimumab – not available unless the patient pays\$100.
Women's and Children's Health Network (W&CHN) SA	Funding of therapeutic drug monitoring , including funding of faecal calprotectin testing		Our gastroenterology department does in house calprotectin testing and commencing Monday 27th August 2018 will be doing in house infliximab testing in order to improve the service to our patients on Infliximab.

## 6. Establish clearer GP referral guidelines and protocols

Protocols and guidelines for the management of aspects of IBD were reported. National consensus statements have been published for acute severe ulcerative colitis and therapeutic drug monitoring. There are State based and regional clinical prioritisation and decision support tools as well as local/regional protocols and formal pathways for care. GESA has recently launched an e- tool to help GPs distinguish between irritable bowel syndrome and IBD.

Queensland Health has a model for extending GP roles with additional skills to develop capacity in specialist areas. The role involves clinical assessment and coordinating ongoing management.

The RACGP provided information on gastroenterology education opportunities for GPs but only one session was focussed specifically on IBD.

There appears to be protocols and guidelines available that could be readily adapted for use. The gap appears to be in the effective dissemination and uptake of the tools, which is a significant challenge for at the specialist to GP interface where the saturation of various condition specific materials is high.

**Table 6. GP Guidelines**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
Concord Hospital NSW	Australian IBD Consensus Working Group	Each one focuses on a field within IBD that is rapidly changing and allows the development of guidelines and auditable data.	This group of Australian and international gastroenterologists and other specialists have completed to date 2 consensus meeting both published in a leading gastroenterology specialty journal Alimentary Pharmacology and Therapeutics. Each one focuses on a field within IBD that is rapidly changing and allows the development of guidelines and auditable data. In 2015 we published the Consensus Statements on Acute Severe Ulcerative Colitis and in 2017 we published Consensus Statements on Therapeutic Drug Monitoring.
Queensland Health	Clinical Prioritisation Criteria - Gastroenterology (State-wide)	Clinical Prioritisation Criteria aim to support equitable assessment of patients regardless of where they live in Queensland; specialist outpatient appointments that are delivered in order of clinical urgency; patients are ready for care at their first specialist outpatient appointment; and improved referral and communication processes between referrers and specialist outpatient services. <a href="https://cpc.health.qld.gov.au/">https://cpc.health.qld.gov.au/</a>	Clinical Prioritisation Criteria (CPC) are clinical decision support tools that will help ensure patients referred for public specialist outpatient services in Queensland are assessed in order of clinical urgency. CPC will be used by both referring practitioners when referring into the Queensland public hospital system and Queensland public specialist outpatient services when determining how quickly the patient should be seen (urgency category). The Inflammatory Bowel Disease component of the Gastroenterology CPC provides guidance on the assessment, referral and categorisation of patients with previously diagnosed or suspected Inflammatory Bowel Disease.
Queensland Health	General Practitioners with a Special Interest (GPwSI) - state-wide	To increase specialty service capacity and patient access to appropriate clinical care. <a href="https://clinicalexcellence.qld.gov.au/improvement-exchange/gpws">https://clinicalexcellence.qld.gov.au/improvement-exchange/gpws</a> (website describes implementation of	The Hospital and Health Service employs a GP with additional skills in a specific clinical area (a GPwSI) to work within a clinical specialty. The GPwSI: is selected by the specialist and works on a sessional basis according to agreed templates; self-selects and sees patients from the Category 2 and 3 waiting lists, performing clinical assessment and coordinating ongoing management.

		an ENT GPwSI at Gold Coast Hospital and Health Service, however this model has now been rolled out in multiple specialties and locations)	Many of these patients would wait much longer to be seen by a specialist due to the large volume of patients on the waiting list; works in close geographical proximity to the specialist and is able to escalate/discuss care as necessary; and largely sees a non-operative cohort releasing specialist time that can be focused toward patients likely to require surgery with higher levels of need/acuity. There are currently four allocated GPwSI positions in Gastroenterology, with a focus on IBD across Queensland. These are located at Cairns, Metro North (The Prince Charles Hospital), Metro South (Princess Alexandra Hospital), and Gold Coast.
CCA	CCA IBD Quality of Care - Patient Experience	Assess quality of care from consumer perspective	Various aspects of the GP interaction and coordination will be described (report pending)
Queensland Health	Health Pathways (state-wide)	Health Pathways is an online manual used by primary care clinicians to help make assessment, management, and specialist request decisions for specific conditions.	Rather than being traditional guidelines, each pathway is an agreement between primary and specialist services on how patients with particular conditions will be managed in the local context. Each health jurisdiction tailors the content of Health Pathways to reflect local arrangements and opinion, and deploys their own instance of Health Pathways to their clinical community. As services across Queensland have implemented Health Pathways, a number have developed pathways specific to the management of Inflammatory Bowel Disease. IBD pathways have so far been developed for: Far North Queensland, Metro South, Sunshine Coast, Wide Bay and Townsville.
RACGP	GP Educational activities		Of 17 face-to-face and e-learning gastroenterology related activities nationally one was focused on IBD and One included some content on IBD

<p><b>Lyll Mc Ewin Hospital, Northern Adelaide LHN</b></p>	<p>Publishing local NALHN protocols for management of acute severe ulcerative colitis, Infliximab infusion protocols, Vedolizumab infusion protocols, Ustekinumab infusion protocols and patient information leaflets for IBD.</p>	<p>Provide knowledge and education to other health care providers within NALHN. Available in local NALHN intranet Policies Procedures &amp; Guidelines (PPG)</p>	<p>Better overall management of IBD patients</p>
<p><b>Royal Adelaide Hospital /Central Adelaide Local Health Network</b></p>	<p>Establish clearer GP referral guidelines and protocols</p>		<p>Not yet – but I am the chair-person of a Gastroenterological Society of Australia (GESA) sponsored e-tool which will be launched at Australian Gastroenterology Week (AGW ) in Brisbane Sept 8-10 which will support General Practitioner’s (GPs) in more promptly and accurately distinguish between Irritable Bowel Syndrome (IBS – a symptom-based condition which could be better managed in primary care – no tissue damage) and IBD (where earlier detection and care can prevent avoidable morbidity and complications). The tool is called “IBS4GPs”.</p>

## 7. Improved consumer knowledge

Activities reported to improve consumer knowledge included

National groups such as AIBDA and CCA provide patient information brochures and online information. Patient information booklets are also produced locally by health networks or topic specific purposes such as pregnancy/fertility, and in one case was reliant on pharmaceutical industry support. There is research underway evaluating consumer decision support tool for ulcerative colitis.

Two sites reported providing IBD patient information evenings on site which is part of a national program of information evenings coordinated by CCA.

The reliance on limited industry support for funding means that materials are not comprehensive and organised as a complete suite of materials that meet consumer need.

**Table 7. Consumer knowledge**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
Liverpool Hospital	myAID: Patient Decision Aid for use in Ulcerative Colitis	Clustered randomised national RCT aimed to demonstrate improved QOL, and UC outcomes through use of a decision aid versus standard care	This is a 4 year CRCT and outcomes include QOL, patient empowerment, medication adherence, reduced anxiety, reduced health care costs and improved work productivity and improved UC
CCA	ccHUB	Provide reliable, current consumer information online	CCA hosted website with information about the illnesses, living with IBD and current research. The website will be further informed in consume need by the CCA IBD Quality of Care - Patient Experience Survey.
AIBDA	Patient and clinician education brochures on IBD including pregnancy and IBD		See GESA website. IBD and pregnancy guidelines should be released by AGW
Simon Knowles	Research	Promote consumer knowledge and improve well-being and disease management outcomes	Promote consumer knowledge and improve well-being and disease management outcomes
Lyell Mc Ewin Hospital, Northern Adelaide LHN	Publishing local NALHN protocols for management of acute severe ulcerative colitis, Infliximab infusion protocols, Vedolizumab infusion protocols, Ustekinumab infusion protocols and patient information leaflets for IBD.	Provide knowledge and education to other health care providers within NALHN. Found in local NALHN intranet Policies Procedures & Guidelines (PPG)	Better overall management of IBD patients

<p>Royal Adelaide Hospital /Central Adelaide Local Health Network</p>	<p>Improved consumer knowledge</p>		<p>We provide content for Crohn's and Colitis Australia's (CCA) regular patient information evenings – the RAH usually alternates each year with Flinders Medical Centre (FMC) in being the professional/Medical partner for the event and it is usually held on site at one of the hospitals, with CCA staff flying down to help coordinate. The RAH IBD Service sends out a regular consumer newsletter (2-3 per year). This is via email and by post and has been funded since inception by soft funding earned by Prof Andrews with after hours (AH) consulting.</p>
<p>Southern Adelaide Local Health Network (SALHN)</p>	<p>Patient education</p>	<p>We have developed (along with CALHN) an education booklet for patients with regard to fertility and pregnancy in IBD. This has been printed with the support of the pharmaceutical industry as a single small grant, but will not be possible when this funding runs out.</p>	<p>We are presenting an educational evening session to CCA for SA in September 2018</p>

### 8. Support for practice management software (IBD specific auditable clinical management software)

There is no national database for IBD, but several sites reported maintaining local or regional databases. An IBD specific clinical management software product was described in SA and is being supported by the SA government. This is the same product described by ANZIBD and has potential as a national database and patient management software. Concord Hospital describes a regional long-standing database utilised for multiple research projects.

**Table 8. Practice management software**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
Concord Hospital NSW	Sydney IBD Cohort (database)	Database for epidemiological studies	The Sydney IBD Cohort is a database of 2,500 IBD subjects that grew from data collected at the Sydney Local Health District, centred around Concord Hospital, Sydney. Data captured in 1980 were kept and allowed for longitudinal studies that determined 1) the mortality rates of Crohn's disease and ulcerative colitis in men and women; 2) the rates of colorectal cancer in IBD subjects. These geographical population-based studies formed some of the few high-quality epidemiological studies to have come from Australia. The database was expanded to report on patient outcomes. The Sydney IBD Organisation has since been in over 7 peer-reviewed publications in major gastroenterology/ IBD journals. Professor Rupert Leong is the current director of Sydney IBD Organisation.
ANZIBD	Clinical Management Software (CMS): Crohn's Colitis Care	CMS plus point of care longitudinal recording of KPIs in IBD care See ANZIBD Consortium or Crohn's Colitis Cure Websites	Cloud based clinical management aiming to capture the care of at least 20000 IBD patients cared for in Australia through use of the CMS
Lyell Mc Ewin Hospital, Northern Adelaide LHN	Establishing an IBD database – currently 500 active IBD patients on the database with 100 on biologics.	Identification of IBD cohort at Lyell McEwin hospital	Better overall management of IBD patients with all information within a single database.
Royal Adelaide Hospital /Central Adelaide Local Health Network	Support for practice management software		There is now IBD-specific clinical management software and SA Health is the FIRST jurisdiction to engage in a contract for its use. This software is being used at the RAH for the last 2-3 months and is obviating the need for accessing paper-based notes, is saving typing (as staff can prepare and print a letter during an encounter) and collects data in a consistent



			<p>fashion so that better outcome assessment nationally can be assessed. SA Health should be congratulated for being an early adopter. The 5 year contract is funded by 2 years free time (as I and others within South Australia (SA) were development partners) and 3 years underwritten by The Hospital Research Foundation).</p>
<p><b>Southern Adelaide Local Health Network (SALHN)</b></p>	<p>Administrative resources and support for clinical management software</p>		<p>Up until 2 years ago our IBD service had access to 0.5FTE admin assistant using “soft money”. This funding was lost and as a result our data base has not been updated since this service ceased. This makes it difficult to provide an overview of the patients under SALHN IBD care. Additionally, the new clinical management software developed by the CCC with the aim of improving patient care will not be possible to use at SALHN without administrative support to assist in data migration. This software, with its inherent transparency and standardisation of clinical management, is likely to improve patient care, and would be beneficial to introduce.</p> <p>Administration support would also assist in sending patients SMS reminders to attend clinic, resulting in fewer missed appointments, and thus better care (we note an increase in missed appts since the loss of our admin officer).</p>

### 9. Increased investing in clinical trials and audit of paediatrics

Activities to improve the transition of young people to adult care were reported at Concord Hospital and Monash Health and planning for more formalised transition support in SA. There are also plans to audit biologic therapy and evaluate patient needs in SA.

**Table 9. Paediatric research and audit**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
Concord Hospital NSW	IBD Clinic, IBD Transition Service	Multidisciplinary and transitional care	Our current IBD Clinic provides multidisciplinary care incorporating IBD dietitian and a psychologist. We receive public and private patients transitioning from Westmead Childrens Hospital.
Monash Children's Hospital	Establishment of young adult IBD clinic	Improve outcomes for young people including during transition	Establishment of clinic with joint paediatric and adult IBD specialists. Survey of patients and prospective audit of Accident & Emergency attendance/admissions.
RCH Melbourne		Providing and outreach service to manage Paediatric IBD patients in Hobart/Tasmania	Start-up of Paediatric IBD clinic once every 3 months in Hobart 1st clinic to start on 10th of August in Hobart as an RCH outreach IBD clinic and concurrently to educate the local Paediatricians regarding management of IBD
Women's and Children's Health Network (W&CHN) SA	Improved consumer knowledge	<b>Comment</b> We are attempting to improve our transition process for young people with IBD and this includes developmentally appropriate education for young people to empower them to manage the disease. A more formalised transition process is evolving.	
Women's and Children's Health Network (W&CHN) SA	Increased investing, clinical trials and audit of paediatrics	<b>Comment</b> We are planning to audit our use of biologics. Part of the project exploring the idea of a nurse led clinic is through developing a questionnaire for young people to assess their needs. Richard Couper has commenced discussion with RAH around young people being involved in some of the adult clinical trials.	

## 10. Explore the effectiveness of medical home funds bundling

No activities relating to funds bundling were reported though some comment of support for the concept were made.

## 11. Other activities reported (not specific to priority areas)

Other activities reported that do not relate specifically to the ten priority areas, or only partially relate to them are listed in **Table 11**.

The most common theme is activities that support gastroenterologist clinical standards such as: The Australian Consensus Working Group, IBD school for advanced trainees, paediatrician gastroenterology training in IBD and surgeon education.

Two activities focussed on regional outreach of specialist services are described at Bendigo and Hobart (paediatrics). There are also activities focussed on outpatients demand management through GP support and prioritisation protocols.

The myAID interventional study previously mentioned for proposed consumer information benefits appears to have aims for improvement of quality of life and reduced healthcare costs.

**Table 11. Other activities**

Name of organisation conducting / reporting	Name of activity	Aim of activity	Description of activity and outcomes
Concord Hospital NSW	Australian IBD Consensus Working Group	Each one focuses on a field within IBD that is rapidly changing and allows the development of guidelines and auditable data.	This group of Australian and international gastroenterologists and other specialists have completed to date 2 consensus meeting both published in a leading gastroenterology specialty journal Alimentary Pharmacology and Therapeutics. Each one focuses on a field within IBD that is rapidly changing and allows the development of guidelines and auditable data. In 2015 we published the Consensus Statements on Acute Severe Ulcerative Colitis and in 2017 we published Consensus Statements on Therapeutic Drug Monitoring.
RCH Melbourne	Providing and outreach service to manage Paediatric IBD patients in Hobart/Tasmania	Start-up of Paediatric IBD clinic once every 3 months in Hobart	1st clinic to start on 10th of August in Hobart as an RCH outreach IBD clinic and concurrently to educate the local Paediatricians regarding management of IBD

<p><b>Queensland Health</b></p>	<p>Clinical Prioritisation Criteria - Gastroenterology (State-wide)</p>	<p>Clinical Prioritisation Criteria aim to support equitable assessment of patients regardless of where they live in Queensland; specialist outpatient appointments that are delivered in order of clinical urgency; patients are ready for care at their first specialist outpatient appointment; and improved referral and communication processes between referrers and specialist outpatient services. See <a href="https://cpc.health.qld.gov.au/">https://cpc.health.qld.gov.au/</a></p>	<p>Clinical Prioritisation Criteria (CPC) are clinical decision support tools that will help ensure patients referred for public specialist outpatient services in Queensland are assessed in order of clinical urgency. CPC will be used by both referring practitioners when referring into the Queensland public hospital system and Queensland public specialist outpatient services when determining how quickly the patient should be seen (urgency category). The Inflammatory Bowel Disease component of the Gastroenterology CPC provides guidance on the assessment, referral and categorisation of patients with previously diagnosed or suspected Inflammatory Bowel Disease.</p>
<p><b>Concord Hospital NSW</b></p>	<p>IBD Endoscopy - Colonoscopy surveillance</p>	<p>Centre of excellence in colonoscopic advanced imaging</p>	<p>Professor Rupert Leong is the Clinical Lead of the Cancer Council Colonoscopy Surveillance update of 2018. He led a group of clinicians and pathologist to revise the statements, evidence level and recommendation grades for surveillance colonoscopy in IBD subjects in order to provide improved outcomes of patients and maximisation of dysplasia sensitivity. Adopting novel technologies such as chromoendoscopy, confocal laser endomicroscopy and Full Spectrum Endoscopy, Concord Hospital is a world-leading centre of excellence in colonoscopic advanced imaging. We receive fellows from around to world to enhance their colonoscopic skills. We perform stricture dilatation and inserted the Australian-first endoscopic biodegradable stent for a patient with Crohn's disease.</p>
<p><b>Susan Connor</b></p>	<p>myAID: Patient Decision Aid for use in Ulcerative Colitis</p>	<p>Clustered randomised national RCT aimed to demonstrate improved QOL, and UC outcomes through use of a decision aid versus standard care</p>	<p>This is a 4 year CRCT and outcomes include QOL, patient empowerment, medication adherence, reduced anxiety, reduced health care costs and improved work productivity and improved UC</p>
<p><b>Concord Hospital NSW</b></p>	<p>IBD School</p>	<p>The goal is to improve the standards of IBD care by addressing gaps in advanced training</p>	<p>In 2016, focus group research identified gaps in the teaching of IBD to gastroenterology trainees. Some gastroenterology advanced trainees had completed 3 years of advanced training in gastroenterology without having seen a single IBD outpatient.</p>

			<p>They were familiar with inpatient management but had no experience with ambulatory care of IBD patients. As such their deficiency in knowledge translated to suboptimal care of patients. IBD School is a workshop of 1.5 days' duration held in October yearly in Sydney. A steering committee designed a two year course and invites gastroenterology trainees from Australia and New Zealand to attend. The focus is on subjects that gastroenterology trainees might have missed during their training. The goal is to improve the standards of IBD care. Half-day is dedicated towards professional development. Yearly feedback to date has been outstanding. Professor Rupert Leong is the director of the IBD School.</p>
Queensland Health	General Practitioners with a Special Interest (GPwSI) – state-wide	<p>To increase specialty service capacity and patient access to appropriate clinical care  <a href="https://clinicaexcellence.qld.gov.au/improvement-exchange/gpws-i">https://clinicaexcellence.qld.gov.au/improvement-exchange/gpws-i</a> (website describes implementation of an ENT GPwSI at Gold Coast Hospital and Health Service, however this model has now been rolled out in multiple specialties and locations)</p>	<p>The Hospital and Health Service employs a GP with additional skills in a specific clinical area (a GPwSI) to work within a clinical specialty. The GPwSI is selected by the specialist and works on a sessional basis according to agreed templates; self-selects and sees patients from the Category 2 and 3 waiting lists, performing clinical assessment and coordinating ongoing management. Many of these patients would wait much longer to be seen by a specialist due to the large volume of patients on the waiting list; works in close geographical proximity to the specialist and is able to escalate/discuss care as necessary; and largely sees a non-operative cohort releasing specialist time that can be focused toward patients likely to require surgery of with higher levels of need/acuity. There are currently four allocated GPwSI positions in Gastroenterology, with a focus on IBD across Queensland. These are located at Cairns, Metro North (The Prince Charles Hospital), Metro South (Princess Alexandra Hospital), and Gold Coast.</p>
Lyell Mc Ewin Hospital, Northern Adelaide LHN	Setting up a dedicated IBD clinic once a week – run by one gastroenterologist (for the last 4 years) and	Streamlining IBD patients into a specialised clinic where clinical management is optimised and decrease issues with overall gastroenterology	Decrease in delay to review NEW IBD patients, decrease in delay to review IBD patients, decrease errors in biologic application to PBS, decrease in need for IBD inpatient admission, decrease in the use of steroids for rescue treatment (when management of

	assisted by second gastroenterologist (alternate weeks for the last 6 months).	waiting list. This allows also coordination of medications to be done in an efficient and timely manner.	IBD optimised) and IBD focused long term management.
<b>Concord Hospital NSW</b>	IBD Sydney (Clinical Group)	The group was to provide clinicians with interest in IBD to meet and discuss difficult cases.	In 2012, Professor Rupert Leong commenced a clinical group named IBD Sydney. The group was to provide clinicians with interest in IBD to meet and discuss difficult cases. These meetings have grown in size and have not coincided with major key opinion leaders visits to Sydney and launch of new drugs. The meetings are well attended – up to 100 members / delegates per meeting comprising of gastroenterologists, general physicians, gastroenterology fellows/ registrars and IBD nurses. IBD Sydney is a “go to” point for industry partners to engage clinician gastroenterologists. Professor Rupert Leong is the current director of IBD Sydney.
<b>Concord Hospital NSW</b>	IBD Infusion Centre	IBD Infusion service co-located with endoscopy to improve gastroenterologist access	Our infusion service is part of the endoscopy recovery area and as such all patients are under the care of gastroenterologists rather than being within a haematology or GP-led infusion service. We therefore can easily review patients who are flaring or develop complications from their IBD IV infusions optimally and efficiently. The infusion service also provides clinical drug trial infusions and some IV iron injections. Concord Hospital is the first Australian hospital to develop the “Protocolised Accelerated Remicade Infusion Service (PARIS)” that reduced infusion times from 2 hours down to ½ hour to increase throughput and patient satisfaction. This protocol is now adopted throughout Australia and led to the change in the drug Product Information reducing the infusion times. Dr Jeff Chang and Professor Rupert Leong conducted a review on the occupational health and safety of biological infusions

<b>Concord Hospital NSW</b>	IBD Microbiome Research and AIM Group	longitudinal research project on the microbiome and IBD	Dr Craig Haifer is our fellow conducting PhD research on the microbiome co-supervised by Professor Rupert Leong and Dr Sudarshan Paramsothy. With the arrival of Dr Georgina Hold and Prof Emad El-Omar we engaged them as clinical research coordinators. Prof Rupert Leong is the clinical lead of the Australian IBD Microbiome Group and will be performing a longitudinal research project on the microbiome and IBD. Dr Viraj Kariyawasam and Dr Sudarshan Paramsothy are collaborators.
<b>St George &amp; Sutherland Clinical School</b>	Australian IBD Microbiome Study		Research to identify microbial signatures which: a) predict disease relapse b) inform response to therapeutic options
<b>RCH Melbourne</b>	Developing the roles of a clinical fellow in Paediatric IBD	To teach GI trainees about good and streamline practices in the management of IBD	Pilot year will good success so far in distributing the care of IBD patients within a multi D team that includes training doctors
<b>RCH Melbourne</b>		Providing and outreach service to manage Paediatric IBD patients in Hobart/Tasmania	Start-up of Paediatric IBD clinic once every 3 months in Hobart 1st clinic to start on 10th of August in Hobart as an RCH outreach IBD clinic and concurrently to educate the local Paediatricians regarding management of IBD
<b>St Vincent's Health</b>	Establishment of a mobile IBD service in regional Victoria	improve quality of IBD care in regional settings	Ongoing
<b>CSSANZ</b>	CSSANZ Spring CME meeting	Surgeon education	Focus on IBD management at annual surgical meeting
<b>Concord Hospital NSW</b>	Funding Seeding Grants	Use of various funding sources to achieve the aims of multiple programs at Concord	Concord have received seeding grants from Ferring, Takeda Pharmaceuticals and research grants from Janssen, Shire and NHMRC Career Development Fellowship to complete these aims.

<p>Lyell Mc Ewin Hospital, Northern Adelaide LHN</p>		<p><b>Comment</b> NALHN comment: Further activities planned for improving the quality of care for people living with IBD is limited by lack of funding and hence lack of expansion. The number of IBD patients in this region has outgrown the current service due to significant population growth and the disadvantaged socio-economic patient cohort. As it stands, the NALHN IBD service is extremely understaffed when compared to other centres in the state and interstate covering the same population. Significant additional funding is required for administrative staff, full time IBD gastroenterologists, full time IBD nurse, colorectal surgeon funded sessions and funded IBD dedicated dietitian required to reach standards set.</p>
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## Appendix 1 IBD stocktake survey contacts

Agency for Clinical Innovation NSW  
Australian College of Mental Health Nurses (ACMHN)  
Australian Inflammatory Bowel Disease Association (AIBDA)  
Australian Primary Health Care Nurses Association (APNA)  
Australian Psychological Society (APS)  
Chief Executive, Northern Territory Department of Health  
Chief Executive, SA Health  
Chief Medical Officer, Australian Government  
Chief Nursing Officer, Australian Government  
Colorectal Surgical Society ANZ (CSSANZ)  
Dietitians Association of Australia (DAA)  
Director-General, ACT Health  
Director-general, Department of Health WA  
Director-General, Queensland Health  
Gastroenterological Society of Australia (GESA)  
Gastroenterological Society of Australia (GESA)  
Gastroenterologists via GESA  
Gastroenterology nurses via GENCA  
Inflammatory Bowel Disease Nurses Australia (IBDNA)  
Pharmaceutical Society of Australia (PSA)  
Primary Healthcare Network jurisdictional contact Adelaide  
Primary Healthcare Network jurisdictional contact Country SA  
Primary Healthcare Network jurisdictional contact NSW  
Primary Healthcare Network jurisdictional contact QLD & NT  
Primary Healthcare Network jurisdictional contact VIC & TAS  
Primary Healthcare Network jurisdictional contact WA

Royal Australian College of General Practitioners (RACGP)  
Royal Australian College of Surgeons (RACS)  
Safer Care Victoria  
Secretary, Department of Health and Human Services Tasmania  
Secretary, Health and Human Services Victoria  
Secretary, Ministry of Health NSW  
The Society of Hospital Pharmacists of Australia (SHPA)