



Interim Australian Standards

Interim Australian IBD Standards:
Standards of healthcare for people
with inflammatory bowel disease
in Australia

2015

**Inflammatory Bowel Disease
Quality of Care Program**



Crohn's & Colitis Australia (CCA) is the peak body representing approximately 75 000 Australians with IBD.

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Interim Australian IBD Standards

Inflammatory bowel disease (IBD) is a chronic and largely hidden disease affecting approximately 1 in 250 people aged 5 – 49 nationally. Australia has one of the highest rates of prevalence and incidence in the world and each year more young people are diagnosed. Over 75 000 Australians are burdened with a constant and often hidden struggle that affects their personal, social and work life¹.

In the 2013 report *Improving Inflammatory Bowel Disease Care across Australia* Pricewaterhouse Coopers identified key problems in IBD care, summarised in two categories:

- increased healthcare utilisation and expenditure due to increasing hospitalisations, productivity losses and other financial costs
- inadequate and inconsistent medical care as a result of short-term management of the disease and inequitable access to support and education.

Crohn's & Colitis Australia (CCA) has obtained Australian Government Department of Health funding, and the endorsement of the peak learned bodies representing important health stakeholders in IBD, to develop the Australian IBD Standards, and to perform a national IBD Audit. The aim of these initiatives is to improve the quality and safety of care for all IBD patients throughout Australia by examining the provision and organisation of IBD care and to provide an evidence-based case for increased IBD resources that is consistent with national needs, is supported by the main stakeholder groups and aligns with government policy objectives.

The CCA Quality of Care Steering Committee is responsible for the development of the Australian IBD Standards and has drawn on the considerable work undertaken by the IBD Standards Group in the United Kingdom. The committee has adopted the six overarching standards established in the UK *Standards for the Healthcare of People who have Inflammatory Bowel Disease. 2013 Update*² and through representation by the main IBD stakeholders, including consumers, adapted the UK implementation standards for the Australian population and healthcare system.

The resulting Interim Australian IBD Standards are released to specify consistent expectations for IBD care for hospitals, healthcare professionals, consumers and IBD stakeholders nationally. The standards will be trialled through the IBD Audit and a public consultation process. It is anticipated that any revisions required will be released in a final Australian IBD Standards in mid-2016.



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¹ Pricewaterhouse Coopers Australia. Improving Inflammatory Bowel Disease care across Australia. March 2013. Available at: <https://www.crohnsandcolitis.com.au/site/wp-content/uploads/PwC-Report-2013-Executive-Summary.pdf> (last accessed 24 August 2015).

² The IBD standards Group. Standards for the Healthcare of People who have Inflammatory Bowel Disease. 2013 Update. Available at: http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf (last accessed 24 August 2015).

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The Royal Australasian
College of Physicians



Standards of care

Standard A: High-quality clinical care

High-quality, integrated clinical care for patients should be based on a multidisciplinary team collaborating within recognised organisational structures and boundaries.

Standard B: Local delivery of care

Care for IBD patients should be delivered locally whenever possible, but with rapid access to specialised services when needed.

Standard C: Maintaining a patient-centred service

Patient-centred care should be responsive to individual needs and should offer a choice of care strategies where possible and appropriate.

Standard D: Patient education and support

IBD care should empower patients to understand their condition and its management in order to achieve the best possible quality of life.

Standard E: Data, information technology and audit

The IBD service should use data, IT and audit to support patient care effectively and to optimise clinical management.

Standard F: Evidence-based practice and research

The IBD service should support service improvement and clinical research, and should be knowledge-based.

Minimum standards

Inflammatory bowel disease (IBD) is a complex condition best managed by a multidisciplinary team approach.

The IBD team should include a:

- gastroenterologist with IBD training
- colorectal surgeon with IBD training
- IBD nurse support with telephone helpline
- dietitian
- psychologist or counsellor
- stomal therapist
- radiologist with an interest in IBD
- histopathologist with an interest in IBD.

Smaller and regional centres may not have these services, so communication and referral pathways should be established with appropriate centres. A nominated local clinician should help coordinate care.

Standard A:

High-quality clinical care

High-quality, integrated clinical care for patients should be based on a multidisciplinary team collaborating within recognised organisational structures and boundaries.

Rationale

The specialist team

The variation and complexity of symptoms between patients, and over time in an individual patient, requires personalised management and engagement between the patient and the professional team.

Professionals must have knowledge about IBD and its effect on patients and their families. They must also have time for continuing professional training and education. A multidisciplinary approach is essential.

The minimum service team for a population of 250 000 is outlined in Standard A1. Hospitals with smaller catchment populations may offer safe and effective IBD services by linking in with larger regional services via appropriate arrangements to enable the service to meet the defined standards of specialist activity and supporting services.

Referral pathways

Protocols and pathways need to be agreed locally to ensure prompt referral and investigation of patients who are suspected of having IBD.

Rapid access to specialist care

Symptoms of active disease are unpredictable: a service must be responsive so that the effects of a relapse on each patient's wellbeing are minimised. Specialised doctors and nurses can decide appropriate courses of action in conjunction with patients.

Use of immunomodulator and biological therapies

- Immunomodulator and biological therapies should be initiated and managed by specialists experienced in their use.
- The aim of treatment should be to establish mucosal healing.

- Ongoing safety monitoring can be part of a shared-care arrangement agreed with patients and their GPs.
- The involvement of a specialist pharmacist is of high-clinical and pharmacoeconomic worth.
- The value of these therapies should be reviewed regularly.

Access to specialist surgical care

Patients requiring pouch or salvage pouch surgery, or intestinal resections, or perianal surgery for IBD, should have these procedures carried out by specialists with appropriate training in centres able to provide the necessary nursing, dietetic and ancillary support.

Nutritional support

Nutritional assessment is important in all stages of IBD. Patients may need simple dietary advice or specific instructions to alleviate symptoms or to meet caloric and micronutrient requirements. A nutrition support team needs to be available for those patients who require complex enteral and parenteral nutritional support.

Paediatric and adolescent care

Paediatric and adolescent care is best undertaken by paediatric gastroenterologists who have access to specialist nursing and dietetic support. These teams should operate in a managed clinical network, which can facilitate shared care and implement transitional care arrangements with adult gastroenterologists.

Implementation standards

Standard A1: The IBD team

A defined IBD team with named personnel should care for patients suffering from IBD. Team members must establish a collaborative approach and may replace each other provided the necessary competencies are present.

One member of the IBD team should be the named clinical lead for the IBD service.

Based on the need for replacements and the defined population of 250 000, the IBD team should have a minimum of:

- 2 FTE consultant gastroenterologists
- 2 FTE consultant colorectal surgeons
- 1.5 FTE clinical nurse specialists with competency in IBD
- 1.5 FTE clinical nurse specialist with competency in stoma therapy and ileo-anal pouch surgery
- 0.5 FTE dietitian allocated to gastroenterology*
- 0.5 FTE administrative support for IBD meetings, IBD database recording and audit.

FTE: full-time equivalent

* With arrangements for replacement in the event of absence

Standard A2: Essential supporting services

The IBD service should have defined and timely access to the following named personnel with an IBD interest and expertise:

- pharmacist
- histopathologist
- radiologist
- psychologist or counsellor
- rheumatologist
- ophthalmologist
- dermatologist
- obstetrician
- nutrition support team
- consultant paediatrician or a combination of consultant paediatrician and an adult gastrointestinal physician interested in adolescent IBD. Both should be working in a paediatric gastroenterology clinical network with appropriate adult and paediatric nursing support
- an established link with a GP to provide a liaison and educational role for local GPs.

Standard A3: Multidisciplinary working

A3.1: IBD team meetings

The IBD team should hold meetings regularly, preferably weekly or fortnightly, to discuss patients with complex needs. These meetings could be part of another established clinical meeting. The outcomes should be recorded in the hospital notes, including the name of the team member who will discuss the advice with the patient.

Patients discussed by the team are likely to include those with: complex needs; perianal disease; aggressive Crohn's disease at risk of requiring a further resection; fistulising disease unable to achieve a sustained steroid-free remission; and indications for biological therapy. Specific criteria for inclusion can be agreed locally.

- Meetings should include all members of the team.
- Attendance should be recorded and minutes kept.
- All decisions at the IBD team meetings should be recorded and relevant audit data noted.
- Topics covered should include a review of all IBD deaths, complex cases, and service issues and development.

A3.2: Medical/surgical interaction

- Patients should have access to parallel or joint surgical-medical clinics that are held at least monthly, at which a recognised adult or paediatric colorectal surgeon interacts with a gastroenterologist in a unit that meets these standards.
- There must be a defined arrangement for joint discussion with patients whose clinical condition does not permit delays until the next suitable clinic.

Standard A4: Referral of suspected IBD patients

- The development of GP guidelines will assist the identification and referral of symptomatic patients in whom IBD is suspected. GPs should be prepared to periodically review their diagnosis in patients with unresponsive, atypical or troublesome abdominal symptoms.
- A communication pathway must be agreed for referral of possible IBD patients for rapid assessment. Such patients should be contacted within two weeks of referral and seen within four weeks, or more rapidly if clinically necessary.
- Newly diagnosed patients, for whom surgery is not an immediate consideration, should be assessed by a medical gastroenterology team.
- Management of all new diagnoses should adhere to contemporary clinical guidelines and should be reviewed by the multidisciplinary team.

Standard A5: Access to nutritional support and therapy

- Patients should have access to a dietitian either directly or via a telehealth option.
- All forms of proven nutritional therapy should be available, including exclusive liquid diet as primary therapy for Crohn's disease.
- Patients with complex nutritional needs must have access to a nutrition support team for comprehensive assessment, management and advice.

Standard A6: Arrangements for the use of immunomodulator and biological therapies

- There must be defined clinical responsibility and protocols for the prescribing, administration and monitoring of these therapies in the appropriate clinical setting.
- Local practice of both immunomodulator and biological therapy should be audited.
- Patients receiving biological therapy and the outcome of biological therapy should be reviewed regularly.

Standard A7: Surgery for IBD

- IBD surgery should be undertaken by recognised colorectal surgeons who are core members of the team, or their supervised trainees, in a unit where the operations are done regularly.
- The nature of operations performed, along with simple metrics on immediate and delayed complications and referral for medical follow-up, should be formally recorded and audited.
- Pouch failure and salvage surgery should be managed in a high-volume specialist unit.
- Obtaining expert pathological assessment before surgery may necessitate referral of cases to a recognised expert.

Standard A8: Inpatient facilities

- Inpatients should, whenever possible, be cared for in a designated, specialist gastroenterology ward area.
- Gastroenterology and colorectal surgical facilities should be in close proximity.
- Wards for IBD patients should have a minimum of one easily accessible toilet per three beds. To provide privacy for patients, ward toilets should have floor to ceiling partitions, full height doors and good ventilation. Facilities should be available for the change and disposal of stoma appliances.
- There must be 24-hour access to intensive care facilities on site.

Standard A9: Access to diagnostic services

- Patients suffering from a relapse of ulcerative colitis should have access to endoscopic assessment within 72 hours if necessary.
- There should be access to ultrasound/MRI/CT/contrast studies and endoscopic assessment within four weeks, maximum, or in more urgent situations, within 24 hours.
- Histological processing should be rapid (minimum standard five working days to report, but with arrangements to report urgent biopsy samples in two days when needed).

Standard A10: Inpatient care

- There should be defined arrangements for admitting IBD patients directly to a specialist gastroenterology ward or area.
- Patients admitted with known or suspected IBD should be discussed with, and normally transferred to the care of, a gastroenterologist or colorectal surgeon within 24 hours of admission.
- IBD specialist nurses should be notified of all admitted IBD patients.
- All IBD patients admitted should be weighed and their nutritional status assessed.
- All IBD patients should have access to a specialist pharmacist for advice on their current and future medical treatment.

Standard A11: Outpatient care

- All patients with confirmed IBD should have their details maintained on a register of IBD patients even if no longer regularly attending outpatient clinics.
- All IBD patients who are not under immediate or ongoing care, including those in remission, should have an annual review and basic information recorded. This review may be carried out in a hospital or community clinic, or by telephone follow-up, and should be undertaken by a healthcare professional with recognised competence in IBD.
- The aspects of management to be reviewed annually should be determined by the IBD team, but would normally include an assessment of disease activity, quality of life, nutritional status and the need for colorectal cancer surveillance. Testing of renal function and bone health should be performed regularly.
- All IBD patients should have access to a dedicated telephone service (IBD Helpline) or an answer-phone facility providing a response by the end of the next working day.

- Patients experiencing a possible relapse should have access to specialist review within five working days.
- IBD patients should be able to choose from a range of options for outpatient care: specialist review in private practice or a hospital clinic; guided self-management with access to support including telehealth services when required; and care in a primary or intermediate care setting with defined links to the IBD team.
- Multidisciplinary IBD team should have regular meetings where complex patients are discussed. These meetings should have multidisciplinary attendance, including medical, surgical, nursing, dietetic, radiological and pathology representation.
- Endoscopy should be performed by endoscopists with training or extensive experience in endoscopy and ileo-colonoscopy in children and adolescents, and appropriate training recognised by the Conjoint Committee for the Recognition of Training in Gastrointestinal Endoscopy (CCRTGE).

Standard A12: Arrangements for the care of children and young people who have IBD

- Children and young people should have the choice of being managed in an age-appropriate environment. In most cases, this will be in a paediatric hospital and involve a paediatric gastroenterologist, a local paediatrician with expertise in gastroenterology and an IBD nurse specialist.
- All children, at least up to their 18th birthday, should have the choice to be referred to a paediatric gastroenterology service for initial investigation and treatment. Follow-up should be provided within a paediatric gastroenterology clinical network.
- The following standards for staffing and facilities apply to services looking after children up to their 18th birthday. The average number of children with IBD for a specialist paediatric gastroenterology unit in Australia is around 240.
 - Age-appropriate inpatient facilities; children's nurses for all inpatient, outpatient and day case episodes.
 - Endoscopy procedures in a child-friendly unit with accredited paediatric anaesthetists.
 - Access to appropriate radiological investigations (including MRI) in a setting suitable for children, by staff trained in performing and reporting in children.
 - Surgeons with expertise in operating on children and young people with IBD.
 - A paediatric dietitian experienced in the use of exclusive enteral nutrition as treatment.
 - A paediatric IBD nurse specialist with an identified role and competence in paediatric and adolescent IBD.
 - A specialist pharmacist with an interest in IBD.
 - Defined access (or a pathway for referral) to appropriate mental health services.
 - Defined access (or a pathway for referral) to a paediatric endocrinologist.
- Appropriate written information and support should be available for a child or young person with IBD and his or her family, including how to access information for schools.
- There should be a written policy and protocol for transitional care. A coordinator should be responsible for the preparation and oversight of transition (for example, an IBD nurse specialist). Discussions about transition should commence between age 15 and 16 years to enable adequate time for patients to plan towards more independent self-care.
- All staff involved in the care of patients up to the age of 18 years should have the required working with children checks or child safety screening as required in the relevant state jurisdiction. Requirements and contacts are outlined on the Australian Government Child Family Community Australia website: **aifs.gov.au/cfca/publications/pre-employment-screening-working-children-checks-and-p**

Standard B:

Local delivery of care

Care for IBD patients should be delivered locally whenever possible, but with rapid access to specialised services when needed.

Rationale

Primary/secondary care interface

At present, the majority of IBD care is provided by healthcare professionals based in secondary or tertiary centres in metropolitan and regional cities. As long as these standards are met, aspects of management could be provided outside such centres in order to take services closer to the patient or offer the patient choice. Effective hub-and-spoke structures enable access to specialised services promptly though they may be geographically separated from the local care.

Many GPs participate in protocol-based, shared care, including the prescription of medication, monitoring immunosuppressive drugs, assessment of bone density, reviewing vaccination status and other aspects of care. This responsibility could extend to the annual review in appropriate circumstances.

Outreach services by specialist IBD nurses may help bring expert care closer to the patient: this is an area for potential development.

Protocols for shared care should be agreed upon by all interested parties, including patient support organisations.

Implementation standards

Standard B1: Arrangements for shared care

- Arrangements for shared care, and the circumstances in which the patient should be referred for hospital care, must be defined between the IBD team and the GP. They must be explained to the patient, supplemented with written information, using clear, straightforward and appropriate language.
- A system for sharing information about test results or treatment changes should be in place through the use of IT, written communication between the GP and care provider or a patient-held or electronic record.
- Treatment with immunomodulator or biological therapies should be initiated by physicians with expertise in their use. Shared-care protocols should be developed to support the ongoing prescription and monitoring of these drugs in general practice.
- Any such arrangements should be made in consultation with the patient.

Standard C:

Maintaining a patient-centred service

Patient-centred care should be responsive to individual needs and should offer a choice of care strategies where possible and appropriate.

Rationale

Patient-centred care

IBD is a lifelong disease that varies in an individual over time. Patient-centred care offers a choice between different models of healthcare delivery according to the severity and complexity of an individual's disease and depending on local facilities and personal preferences. Options include hospital outpatient or private practice care; GP-based shared care; and supported, self-managed care. Arrangements should recognise that some patients wish to be engaged actively in all decisions while others prefer a more passive role.

Each model of care requires appropriate clinical support and an administrative infrastructure. Self-managed care must be properly organised and maintained to be safe and effective.

Complementary and alternative medicine or therapy (complementary medicine) is used by a significant proportion of IBD patients. There are substantial gaps in the regulation, consumer protection, efficacy and evidence information on complementary medicine for patients and healthcare professionals. It is important for clinicians to have a full picture of all conventional medicine and complementary medicine that patients use to manage their health care.

Implementation standards

Standard C1: Information on the IBD service

All patients should have information describing the IBD service including the means of access, how they can request discussion of their case at an IBD team meeting, and how to seek a second opinion. It should also explain how patients could give feedback and contribute to service development.

Standard C2: Rapid access to specialist advice

There should be a clear process by which patients can obtain access to advice and support by the end of the next working day. Ideally there should be a choice of telephone or email contact.

Standard C3: Supporting patients to exercise choice between treatments

Patients should be offered a choice in their treatments after receiving the necessary support and information where this is medically appropriate and safe. This might include a choice between drug treatment and dietary therapy for Crohn's disease or between rescue medical therapy and surgery during a severe attack of ulcerative colitis. Patient choice to engage in complementary medicine should be respected. Patients should be encouraged to disclose all complementary medicine to those involved in their IBD management to promote safe health care.

Standard C4: Supporting patients to exercise choice between different follow-up care models

Patients should be supported in their choice of follow-up care and take active responsibility in participating in their ongoing care. Follow-up care may be in a private practice or outpatient clinic setting, shared care with their GP, or supported self-management. Patients should have written information explaining what arrangements have been agreed.

Standard C5: Involvement of patients in service improvement

Patients should have a voice and direct involvement in the development of the IBD service, which must demonstrate that mechanisms are in place to obtain and respond to patient feedback.

Possible mechanisms include:

- patient experience surveys and comment cards
- regular meetings with patients to discuss service improvement
- open days with discussion and open forums to encourage feedback
- involving patients in project planning and service development groups
- patient opinion website.

Standard D:

Patient education and support

IBD care should empower patients to understand their condition and its management in order to achieve the best possible quality of life.

Rationale

Patient education

Patients who are well informed about their condition and its treatment have a greater chance of achieving a better quality of life. They should have a clear understanding of the service being offered to them and how to access support. This knowledge will allow them to adapt to the social and psychological impact of IBD.

Implementation standards

Standard D1: Provision of information

- Patients should be offered relevant information about their care and treatment options at all stages of their illness. This should be delivered by an identified member of the team.
- Information should be appropriate to the age, understanding and communication needs of patients and their carers.
- Clear, written information about IBD should be provided in outpatient clinics, wards, endoscopy and day-care areas.
- Information should be available in languages other than English if required, and in a variety of formats including written, audiovisual, and web-based, when appropriate.
- Informed consent should be obtained by a member of the team and written in clear, simple language. A member of the team should ensure patient understanding before signing.
- Patients being considered for surgery, especially pouch surgery or ileostomy, should be offered written, audiovisual or web-based information. Whenever possible, they should have an opportunity to talk with those who have had pouch surgery or a permanent ileostomy. They should also be provided with information about their post-operative care before discharge.

- Information should be provided to all inpatients about their follow-up care before discharge from the ward

Standard D2: Education for patients

Nominated members of the IBD service should provide educational opportunities for patients and their families including:

- disease education
- treatment options
- information about nutrition
- information about medicines
- self-management strategies.

Standard D3: Patient-support groups

- Patients should be provided with contact information for the relevant patient organisations. There should be clearly defined links between the IBD team and these organisations, including Crohn's & Colitis Australia.
- A nominated member of the IBD team should support patient education forums, whenever possible.

Standard E:

Data, information technology and audit

The IBD service should use data, IT and audit to support patient care effectively and to optimise clinical management.

Rationale

Data, IT and audit

Developing a service which provides high-quality, benchmarked care to patients is facilitated by the systematic, structured collection of data, ideally at the point of patient contact. These data can be used by stakeholders, as described below. In the future, benefit will be derived from consolidating local data into a central, anonymised IBD registry to provide a dataset of IBD patients.

Patients

By having instant access to patients' disease history, medication and other relevant details, IBD teams will provide a more responsive, safer service to patients. Teams will be able to support patients at home by telephone, email or via patient portals, offer alternative care pathways and support the monitoring and outcomes of treatments. In the future, patients may have access to their personal data to allow greater understanding of their condition and to support self-management, for example via patient portals.

IBD teams

Using robust IT systems to support care of IBD patients will enable the delivery of efficient, cost-effective, high-quality patient-centred care.

Hospital management

The ability to demonstrate patient outcomes, the quality of services and the appropriate use of high-cost drugs will assist hospital management.

Audit

The collection of data will facilitate continuous, high-quality prospective audit of all aspects of clinical care focused on patient outcomes. Participation in audit will allow the benchmarking of the quality of care against Australia-wide data as well as devolved regional data.

Future IBD audits and quality improvement programs will enable services to develop action plans for improvement and inform local and national planning and research.

Research

Development of cohorts of well characterised patients will become a significant local, national and international research resource.

Implementation standards

Standard E1: Register of patients under the care of the IBD service

Every IBD service should maintain a local register of all diagnosed IBD patients (including those who are not currently being managed in the centre) recorded on a searchable database with adequate clerical support.

Standard E2: Using an IBD electronic clinical management system

IBD services should implement an electronic clinical management system that records patients' disease histories and treatments.

Standard E3: Participation in audit

- Every IBD service should take part in regular audits, including national IBD audits.
- Outcomes for patients receiving biological therapies should be recorded.
- Outcomes of all emergency colectomy, ileo-anal pouch and abdominal operations for Crohn's disease should be submitted to national audit and data collection.
- All IBD deaths must be fully discussed at the IBD team meeting and the outcome of the discussion recorded.

Standard F:

Evidence-based practice and research

The IBD service should support service improvement and clinical research, and should be knowledge-based.

Rationale

Training and education

The IBD unit should offer high-level training to healthcare professionals involved in IBD care in primary, secondary and tertiary care settings to enable them to provide skilled, specialist and patient-centred care at high standards.

Practitioners wishing to provide IBD services should declare a specialist interest and should be named members of the IBD team.

Research

The principle of a knowledge-based service requires that research activities be identified and prioritised.

Implementation standards

Standard F1: Training and education

- All members of the team should be expected and enabled to participate in local and national professional educational activities to maintain their competence and knowledge.
- Advanced nursing practitioners should have access to medical support as well as nursing supervision.
- Specialist pharmacists involved in drug monitoring and other medical therapy clinics should have access to medical support and pharmacy supervision.
- The IBD team should provide IBD awareness and education opportunities for GPs. These activities should focus on the initial presentation of IBD and advances in treatment.

Standard F2: Research

- IBD services should encourage and facilitate involvement in multidisciplinary research through national and international research projects and registries.
- Patients should be given the opportunity to participate in clinical trials on- or off-campus and to provide samples for approved projects.

Standard F3: Service development

- IBD teams should participate in local and national activities intended to improve the quality of IBD care and services.
- IBD teams should take an active part in clinical network arrangements and events with other IBD services.
- IBD teams should be encouraged to hold an annual review day to reflect on their service and, where appropriate, to consult with interested parties.

