Optimising care for patients with Inflammatory Bowel Disease:

- Rural patients’ burden of disease and perceived treatment barriers
- Outcomes of transition care and
- Evaluation of simple clinical tools for outpatient management of ulcerative colitis

A thesis submitted in fulfilment of the requirements for the degree of

MASTER OF PHILOSOPHY
(MEDICAL SCIENCE)

By

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January, 2016
Declaration

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Alice L Bennett             Date
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Abstract

This thesis by publication examines how facets of Inflammatory Bowel Disease (IBD) care could be optimised in an aim to improve health outcomes of patients. Despite its high prevalence within the community, care of IBD patients is often sub-standard due to various obstacles and lack of qualitative and quantitative data relating to what is actually happening to this cohort. This thesis evaluates three important aspects of IBD care: rural care, transition (from paediatric to adult) care and outpatient care, with the aim to address this gap in knowledge and provide data to guide future IBD interventions.

The first study accepted for publication in Chapter Two: Rural Inflammatory Bowel Disease care, examined the disease outcomes in rural patients with IBD, reviewed perspectives regarding barriers to achieving optimal rural IBD care and defined non-gastroenterologist healthcare professionals’ (HCPs) exposure to and knowledge of IBD. It aimed to determine whether rural patients have inferior disease outcomes due to their rural location compared to their metropolitan counterparts. The study found that there were no significant difference in disease outcomes of complications, hospitalisations, surgery and steroid use between rural and metropolitan cohorts, but variance in clinical practice was noted.

This study is important as it is the first of its kind to compare outcomes between these two cohorts and describe perspectives of this topic from key stakeholders. This data is vital if used to guide the development of appropriate interventions to enable equality of access and quality of care for patients with IBD living in rural locations.
The second study accepted for publication in *Chapter Three: Transition Inflammatory Bowel Disease care*, investigated psychosocial and disease outcomes of patients with paediatric onset IBD who had undergone transition from paediatric to adult care and their perspectives of the process. It aimed to investigate whether the current transition processes negatively impacted on key physical and psychosocial outcomes. The study found that the transition process did not appear to adversely affect these outcomes following comparison to a matched cohort who had not undergone the transition process. However, patients had poor knowledge of their transition plan and many were not strongly prepared for transition. A high degree of psychological disorders in both cohorts was noted with poor utilisation of psychological services.

The findings of this study are valuable as currently little data exists about what is actually happening to this cohort and what their perspective are. It also highlights the fact that current transition care practices could be optimised. This data contributes to a foundation on which future transition practices can be designed.

The third published study in *Chapter Four: Outpatient Inflammatory Bowel Disease care*, investigated the availability of educational tools aimed at supporting primary care physicians in the care of outpatient IBD patients through a systematic review of the literature. The study found that few non-expert IBD management tools or guidelines exist compared with those used for other chronic diseases such as asthma. Furthermore, scant data have been published regarding the usefulness of such tools including IBD action plans and associated supportive literature.
These findings are important as it demonstrates a gap in the existence of vital education tools despite the widespread number of patients with IBD-related healthcare issues cared for in the primary care setting. Additionally, data suggests that primary care physicians IBD knowledge and comfort in management is suboptimal.

The final published study, also in Chapter Four: Outpatient Inflammatory Bowel Disease care reflects on the previous results of the third study and reinforces the concept that timely intervention and proactive management is ideal to optimise the care of people with Ulcerative Colitis (UC) in the community. The study described the development and evaluation of patient education guides and an UC action plan for non-specialist and primary healthcare practitioners which aim to support safe, evidence-based outpatient management of UC. All tools were critically appraised by key stakeholder groups and our now freely available to download at an online IBD support group.

This study is significant as it freely provides three key educational tools which address a need recognised in the previous paper. It may serve as a guide to improve the care of outpatient UC patients, through optimising primary health care practitioner knowledge and empowering patients.

In conclusion, this thesis provides new and robust insight into what is currently occurring in several key IBD cohorts and describes key data and tools which address barriers to optimal IBD care. Furthermore, it provides key patient perspectives in each area that historically is lacking.
Publications resulting from this thesis


**Abbreviations**

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<tr>
<td>5ASA</td>
<td>5-aminosalicylic acid</td>
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<td>CCF</td>
<td>Congestive Cardiac Failure</td>
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<td>DM</td>
<td>Diabetes Mellitus</td>
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<td>ECCO</td>
<td>European Crohn’s and Colitis Organisation</td>
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<td>RRMA</td>
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<td>UC</td>
<td>Ulcerative Colitis</td>
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CHAPTER ONE

INTRODUCTION
1.1 Overview

In the current medical era, barriers to the optimal care of patients with Inflammatory Bowel Disease (IBD) are present. In three broad areas: rural care, transition care and outpatient care, limited data exist regarding these barriers. These cohorts are not niche groups, as a significant number of patients live in regional and remote areas\(^1\); up to 25% of patients have disease onset prior to 18\(^2\) and most care is delivered in the ambulatory setting\(^3\). Consequently, a significant proportion of IBD care is covered by examining barriers in these three areas. Despite this, most current research focuses on acute in hospital care and drug therapies rather than systems of care and health delivery approaches. A need for more detailed information on the barriers to optimal IBD care in the three areas exists. This will assist in defining and understanding the evolving challenges of holistic care for this cohort. This thesis presents qualitative and quantitative data that addresses this issue.

1.2 Thesis outline

*Chapter 1* introduces the broad field of IBD and describes current aspects of the Australian context. It then defines the focus of the research (the barriers to optimal care of IBD patients in three broad areas: rural care, transition care and outpatient care) and presents the research question to be addressed in this thesis. Subsequently, the research aims, outline and methods are described. The chapter closes with a discussion of the significance of the research.

*Chapter 2* introduces the area of rural IBD care and includes the published manuscript produced from the project.
Chapter 3 introduces the area of transition IBD care and includes the published manuscript produced from the project.

Chapter 4 introduces the area of outpatient IBD care and includes the two published manuscripts produced from the project.

Chapter 5 discusses the relevant findings from the data and how they integrate together in the broad field of IBD care. It discusses the contribution to knowledge, problems encountered and future directions of the research.

Chapter 6 summarises the key findings and overall significance of the work.

1.3 IBD general

IBD is a chronic and complex inflammatory disorder of the gut, characterised by a relapsing and remitting course\(^4\). An autoimmune disorder in its origin, Crohn’s Disease (CD) and Ulcerative Colitis (UC) are the principle subtypes and it is often associated with high morbidity and a reduction in health related quality of life\(^5\). It is thought to arise as a result of an interaction of environmental and genetic factors with increasing evidence to suggest that alterations in enteric bacteria play a contributing role\(^6\).

Despite being predominantly in developed countries of the world\(^7\), the incidence appears to be increasing steadily in developing countries, indicating its emergence as a global disease\(^8\). Onset is usually in the second and third decade with a further peak in incidence in the seventh
However, a large burden of disease arises in paediatric years with evidence to suggest this has a more active course. Medical therapy currently does not exist to cure the disease and consequently patients live with a lifelong illness, potentially enduring considerable physical and psychosocial symptom burden. Current treatment strategies aim to prevent flares and if unavoidable, limit their impact, with the recent era seeing the introduction of new biologic therapies.

### 1.4 Australian context

Australia has one of the highest rates of prevalence and incidence in the world, affecting approximately 1 in 250 people aged between 5 and 49. In 2005, around 61,000 Australians were living with IBD – an estimated 28,000 with CD and 33,000 with UC. By 2020, the number of people with UC is projected to increase by 25% to over 41,000.

An estimated $100 million per annum is spent on national hospital costs for IBD, with hospitalisations increasing by 6% per year for the last 10 years. Productivity losses attributable to IBD in 2012 were estimated at $380 million, while $2.7 billion of financial and economic costs were associated with management of IBD.

Despite this substantial health and economic burden, the current model of care for IBD in Australia is largely inequitable, untimely and unspecialised. At present, traditional reactive models characterised by utilisation of acute services when patients are unwell and lack of contact when the patient is well, exist and are not appropriate for the chronic nature of IBD. Furthermore, important holistic and continuous care aspects are fragmented and it is evident
that there is a gap in the coordinated patient pathways, services and resources across the country.

If specific areas of IBD care are reviewed certain inadequacies are highlighted. Firstly, a lack of multidisciplinary teams, investigation and treatment facilities and access to specialist services secondary to distance can be seen for Australian rural residents\textsuperscript{13}. Additionally, in many rural and remote areas where specialist gastroenterologist services are absent the majority of long-term follow-up care is carried by primary HCPs, general physicians and occasionally visiting or resident surgeons. Often in these circumstances, a lack of experience in acute and chronic management of IBD impedes optimal care\textsuperscript{14}.

Secondly, in Australia as in most other countries, transition practices for IBD are highly variable and often involve a physical transfer of the patient rather than a coordinated, comprehensive and supportive process\textsuperscript{15}. This is despite a survey of adult and paediatric gastroenterologists reporting that such a process is important\textsuperscript{15}. The lack of structure may influence disease and quality of life outcomes, but to date this has not been formally assessed.

Finally, with regards to outpatient care, a deficiency in IBD patient support and education tools and clear and consistent guidelines for ambulatory care management in Australia exists. In addition to primary HCPs lack of high level of IBD knowledge\textsuperscript{14} or confidence. This serves as a concerning aspect of IBD care\textsuperscript{16,17}. 
1.5 Areas where specific barriers to delivering optimal IBD care are noted

Common and unique barriers are experienced by chronic disease groups when accessing and receiving care. A systematic review by Fradgley et al\textsuperscript{18} reviewed quantitative articles describing barriers to specialist outpatient services. The largest proportion of studies reported acceptability barriers (75.7\%), of which demographic disparities (44.6\%) were reported across all diseases. Other frequently reported barriers included inadequate need assessment, information provision, or health communication. Unique barriers were identified for oncology, mental health, and COPD samples.

Barriers to optimal care for patients with IBD, also a chronic disease, are encountered on a day-to-day basis in tertiary centres. These obstacles hinder coordinated models of healthcare and thus potentially negatively impact on health outcomes. Three specific areas of IBD care harbour individual and unique issues and have been highlighted in the literature to varying degrees. These areas of IBD care and management require further attention in order to formulate strategies to address and overcome them, thereby attempting to improve the IBD model of care in Australia.

1.5.1 Rural IBD Care

The first area of IBD care is that of rural patients living with the disease. Despite residents of rural areas being increasingly identified as people at risk of health disparities\textsuperscript{19}, little published data exists regarding the level of disease burden in rural patients with IBD and how this compares with what we know about urban populations. Distance-related obstacles exist in the rural setting, specifically a lack of investigation and treatment facilities and limited
access to specialist services\textsuperscript{13}. Often these services are only needed intermittently, and care can, in theory, be directed centrally, yet delivered remotely when the patient, the local doctor and the central specialist team maintain good contact. In order to ascertain how best to design and deliver this type of specialty treatment, it is important to understand what is really happening to our rural IBD patients and to understand their perspectives on this issue.

\subsection*{1.5.2 Transition IBD Care}

The second area of IBD care concerns transition care involving transfer of an adolescent patient from paediatric to adult care. In young people with chronic diseases this process can be a significant barrier to optimal medical care provision\textsuperscript{20}. Despite it being a major milestone in the life of a young person it is often poorly done increasing the risk of adverse outcomes relating to physical, social and psychological aspects of a patient’s life\textsuperscript{21-23}. Ideally the process should be coordinated, comprehensive and supportive and have the ability to take into account the complexity of the psychological and physical health problems for the patient and their family\textsuperscript{24}.

Currently, practical recommendations for transitioning IBD patients have been promulgated\textsuperscript{25}. However, as yet, these proposals lack actual outcome data and have omitted patient perspectives. Thus, it is not yet clear whether these recommendations would improve health outcomes. It is vital to therefore obtain outcome and patient perspective data to critically appraise current practices and inform the development of interventions intended to improve transition outcomes.
1.5.3 Outpatient IBD Care

The third area of IBD care relates to outpatient treatment and in particular the outpatient management of UC. The majority of UC care occurs in the outpatient setting, where most people with UC do not need steroids or immunomodulators\textsuperscript{3}. Despite this, care is focussed on specialist level guidelines for the more difficult cases. Whilst this knowledge and practice may be second nature to specialist gastroenterologists, the patients’ primary HCP often has minimal IBD exposure and consequently knowledge of its management is often limited\textsuperscript{14}. This is important as many IBD patients present to their primary HCP with symptoms of IBD prior to diagnosis and in the event of a flare. Written action plans for other chronic illnesses such as asthma have been shown to improve health outcomes\textsuperscript{26}; however, little data exists regarding the usefulness of an IBD action plans and associated supportive literature for the management of mild-moderate UC.

1.6 Research question

Currently, several facets of IBD care hold specific challenges. Certain obstacles can be generalised to the international setting, whilst others are exclusive to the Australian healthcare context. These issues have the potential to impede optimal healthcare delivery to IBD patients, thereby jeopardising the physical, social, psychological and overall quality of life of those concerned, whilst concurrently increasing the economic healthcare burden.

The over-riding research question is what is actually happening in the Australian context in each of the areas of IBD care; what are the perspectives of the key stakeholders in each cohort and what are the ways to address the issues raised?
1.6.1 Rural IBD Care

Minimal qualitative data currently exists regarding the level of disease burden in Australian rural patients with IBD. Furthermore, data has not been presented regarding the degree of difference, if any, compared with their urban counterparts. A number of patient and practitioner perceived barriers exist in obtaining optimal management of these patients, potentially influencing disease outcomes, but none have been published to date. In order to develop strategies to overcome potential barriers to care and to ensure optimal health outcomes for rural IBD patients, we need to know what is actually happening to this cohort and their treatment experience and perspectives on the issue. This data coupled with perspectives from their treating practitioners may then be used for practical recommendations in the future.

1.6.2 Transition IBD Care

The topic of transition care has received significant attention in the literature\textsuperscript{27-30} with considerable debate around the most effective way to achieve a smooth transition. Despite this, there is currently only extremely scant outcome data in IBD and none to our knowledge which compares findings to a matched cohort of non-transition patients. Furthermore, patient treatment experience and perspectives on the issue have not been published to compare with current gastroenterologist and IBD nurse opinions. This data is vital to critically appraise current practices and inform the development of interventions intended to improve transition outcomes.

1.6.3 Outpatient IBD Care

Outpatient care of UC in Australia lacks consistency and guidance, which is sub-optimal given the substantial proportion of mild-moderate IBD\textsuperscript{31,32} which can be managed outside of
tertiary institutions. Whilst several, specialist-targeted, international UC guidelines exist\textsuperscript{33-35}, we do not know how many, if any, exist for primary HCP to support them managing patients in the outpatient setting.

1.7 Research Aims and Hypotheses

The research problem is investigated with the following aims and hypotheses:

1.7.1 Rural IBD care

Aims

- Define the disease burden and treatment experience of IBD in patients living in rural areas and compare it to a matched metropolitan cohort.
- Identify perceived barriers to optimal care of patients with IBD in the rural setting compared with their urban counterparts.
- Examine rural practitioner and patient perspectives.
- Identify means by which any issues identified may be addressed.

Hypotheses

- \textit{Primary hypothesis}: Patients with IBD, who live in a rural setting, have an increased burden of disease (defined by number of hospitalisations, surgeries, steroid use and complications) compared with their urban counterparts.
- \textit{Subsidiary hypotheses}: Rural patients and practitioners have opinions regarding perceived barriers to optimal IBD care.
1.7.2 Transition IBD care

Aims

• Identify and describe the physical, social and psychosocial outcomes of a cohort of young adults who have already experienced the transition process.

• Compare data to the outcomes of patients with adult onset IBD of similar disease duration (to ascertain whether the transition process itself may have influenced outcomes).

• Obtain patient perspectives regarding the transition process.

Hypotheses

• *Primary hypothesis*: Paediatric onset IBD patients who transition to adult IBD care have worse physical, social and psychosocial outcomes compared with patients with adult onset IBD with similar disease duration (defined by number of hospitalisations, surgeries, steroid use and complications).

• *Subsidiary hypotheses* Young adults with paediatric onset IBD have different perspectives regarding their transition into adult care compared with adult and paediatric gastroenterologists.

1.7.3 Outpatient IBD care

Aims

• Investigate the availability of non-expert educational tools for the outpatient care of UC patients.

• Describe and evaluate the development of a set of tools to support primary care physicians in the outpatient care of patients with UC.

• Launch the tools into mainstream use.
Hypotheses

- Primary hypothesis: A paucity of IBD outpatient care guidelines and information tools exists for primary care physicians.

1.8 Research outline

A brief overview of the methods used for each section is outlined below. Specific details of each study are outlined in the manuscripts in subsequent chapters.

1.8.1 Rural IBD Care

Research strategy

An existing Southern Adelaide IBD data base was reviewed. Patient disease characteristics were examined between rural and metropolitan patients to investigate any difference in disease outcomes. To determine whether this is was a reflection of referral bias or a real difference; this was compared to a prospective General Practitioner (GP) cohort collected from Mount Gambier. Cohorts were compared with the use of a questionnaire. A separate survey was used to address the perspective of IBD patient’s in Mount Gambier on issues such as access to services and to assess their knowledge of their illness.

Key stakeholders in the care of rural patients (rural IBD surgeons, GPs and physicians and metropolitan IBD nurses) were surveyed using a questionnaire. Information relating to current job roles and exposure to IBD, service provision to IBD patients, interest in IBD and level of IBD knowledge was obtained. Questions relating to perceived barriers to optimal care of IBD patients were also included.
Study population

The study populations included rural patients with a diagnosis of IBD with a comparative metropolitan cohort and rural service care providers including rural GPs, general physicians and surgeons and metropolitan IBD nurses.

Ethics

- Initial title of project: Rural patients with Inflammatory Bowel Disease (IBD) – burden of disease and perceived barriers to treatment
  - Southern Adelaide Clinical Human Research Ethics Committee
    - Approval No: 365a.12
    - Approval Period: 09 January 2013 to 08 January 2016 (Research commenced 2014)

1.8.2 Transition IBD care

Research strategy

A cohort of young adults with a diagnosis of paediatric onset IBD who had transitioned from paediatric to adult care within the last 10 years was identified from an IBD database. This cohort was surveyed with questions relating to demographics, disease specific information and their transition experience. This data was coupled with recorded information in the Women’s and Children’s Hospital case notes regarding pre-arranged adult healthcare appointments.

Outcomes were compared to a cohort of IBD patients of similar disease duration but receiving all care from adult health services (to avoid large age bias), using the same questionnaire.
Study population
The first cohort included patients with paediatric onset IBD, who had undergone transition from paediatric to adult care within the last 10 years. The second cohort was a comparative IBD patient cohort of similar age, who had not undergone the transition process.

Ethics
- Initial title of project: Outcomes of patients with paediatric onset Inflammatory Bowel Disease following transition into adult care – what do we know?
  - Women’s and Children’s Hospital Network Human Research Ethics Committee
    - Approval Period: 10 January 2013 to 10th January 2016
    - Approval No: REC2518/11/2015 (LNR – HREC/12/WCHN/95)
  - Royal Adelaide Hospital Research Ethics Committee
    - Approval Period: 10 January 2013 to 10th January 2016
    - Approval No: REC2518/11/2015 (LNR – HREC/12/WCHN/95)
  - Southern Adelaide Clinical Human Research Ethics Committee
    - Approval Period: 06 May 2013 to 06 May 2014
    - Approval No: 195.13
  - Research commenced 2014

1.8.3 Outpatient IBD care

Research strategy
A systematic review was conducted to investigate what non-specialist tools, action plans or guidelines for IBD were published in readily searchable medical literature. This was compared to those which exist for other chronic conditions.
Three IBD clinical tools aimed at supporting primary HCPs in the outpatient management of IBD were drafted at a previous “Clinical Insights” meeting in 2013. The project involved feasibility testing whereby the tools were shown to a wide group of stakeholders (gastroenterologists, primary HCPs and UC patients), who were asked to complete a short questionnaire based upon their opinions of the tools. Questions related to usefulness, layout, content and safety concerns. Data was fed back to the original steering committee and the documents were finalised. They were then launched into mainstream Australian use in 2014.

Study population
IBD service care providers including gastroenterologists and primary HCPs and UC patients.

Ethics
- Initial title of project: Non-specialist outpatient management of ulcerative colitis (UC)
  - the usefulness and acceptability of three clinical tools
    - Royal Adelaide Hospital Research Ethics Committee
      - Approval No: 130932
      - Approval Period: 30 September 2013 to 30 September 2016 (Research commenced 2014)

1.9 Significance of research
The research provides quantitative and qualitative data about the disease burden in two defined cohorts of IBD patients in Australia and educational tools to assist in the management of outpatient UC. Currently, similar data is lacking and hence the thesis can help to inform discussion about how to improve IBD models of care in Australia and thus optimise the
physical and psychosocial wellbeing of IBD patients. The information should be of value for individuals with IBD, HCPs and the public health sector.

1.9.1 Patients with IBD

Three discrete populations of IBD patients have historically had little research undertaken regarding their IBD healthcare practices. This data could be used to inform healthcare policy makers to optimise existing systems to ensure coordinated, comprehensive and effective models of care. Through these new and improved practices it is hoped that patients would benefit through reduction in physical and psychosocial morbidity and improve their patient experience.

1.9.2 Healthcare practitioners

Through access to freely available educational support tools tailored to non-specialist care and improved cohesive and coordinated models of IBD care, primary HCPs will benefit. Furthermore, if outpatient management by primary HCPs is optimised, gastroenterologists may benefit through reduction in unnecessary admissions, mismanagement of mild-moderate UC and frequency of follow-up review appointments for mild disease.

1.9.3 Public health sector

Existing Australian data suggests that targeted IBD services have shown to improve patient care and lead to decreased morbidity, decreased surgical referral and optimal outcomes\textsuperscript{12}. At a public health level, holistic and multidisciplinary care has shown to reduce health system costs due to a reduction in admission and bed days\textsuperscript{12}. Better quality healthcare practices and policies can lead to better service integration and patient experience and consequently improvement in healthcare costs and utilisation.
This missing data has the potential to guide future IBD practices and provide opportunities to minimise avoidable morbidity. Subsequently, this may potentially reduce direct healthcare costs and indirect costs via productivity. Given that IBD is a complex chronic disorder, data may also be extrapolated for other chronic disease and consequently, funding bodies, policy makers and in general the wider community may benefit.

1.10 Conclusion

Due to the complexity of IBD, combined with the high morbidity, chronicity, unpredictability and the potential for complications; close and continued collaboration between patients, specialist medical team and multi-disciplinary facilities is vital. Through this research, important missing data has been obtained potentially forming a guide for future health care practices which aim to optimise the care of specific groups of IBD patients.
CHAPTER TWO

RURAL INFLAMMATORY BOWEL DISEASE CARE
2.1 Introduction

Despite literature documenting disadvantaged healthcare and consequently several worse health outcomes in some rural communities compared with those residing in urban regions\(^3\)\(^6\)\(^3\)\(^8\), little published data exists regarding the level of disease burden in rural patients with IBD. Additionally, limited knowledge regarding patient and rural practitioner perspectives on the barriers to optimal medical care exists. This data is required to reveal if there is a true difference and if present what barriers exist contribute to this disparity. With this knowledge programs can be developed to enable equality of access and quality of care for patients with IBD living in regional and remote locations.

This chapter includes a manuscript accepted for publication titled “Rural Inflammatory Bowel Disease care in Australia: disease outcomes and perceived barriers to optimal care” which details a project aimed at addressing this issue. It describes the background to the research question, methods used to obtain the data, results and discussion.
Statement of Authorship

Title of Paper | Rural Inflammatory Bowel Disease care in Australia: disease outcomes and perceived barriers to optimal care.
Publication Status | ✓ Published

Principal Author

Name of Principal Author (Candidate) | Alice Bennett
Contribution to the Paper | (1) conception and design of the study
(2) acquisition of data
(3) analysis and interpretation of data
(4) drafting the article
(5) revising the article for critically for important intellectual content
(6) final approval of the version to be submitted
Overall percentage (%) | 60%
Certification: | This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.
Signature | Date 11.12.2015

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate to include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

Name of Co-Author | Matthias Wichmann
Contribution to the Paper | 5%
(1) revising the article for critically for important intellectual content
(2) final approval of the version to be submitted
Signature | Date 15.12.2015

Name of Co-Author | Jong Khen Chin
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<tr>
<th>Name of Co-Author</th>
<th>Peter Bampton</th>
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Rural Inflammatory Bowel Disease care in Australia: disease outcomes and perceived barriers to optimal care.

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Abstract

**Background:** This study aimed to describe and compare disease outcomes in rural patients with Inflammatory Bowel Disease (IBD), review perspectives regarding barriers to optimal rural IBD care and define non-gastroenterologist healthcare practitioners’ exposure to and knowledge of IBD.

**Method and Materials:** Rural patients who had previously completed an IBD questionnaire were identified from a tertiary hospital IBD database and matched for disease, age and gender to metropolitan patients from this same database. A further rural IBD cohort was identified from a rural general practice database in Mount Gambier, South Australia. These patients were invited to complete the same IBD questionnaire relating to disease characteristics and a further questionnaire relating to perceived barriers to optimal care. A questionnaire was also sent to rural healthcare practitioners seeking perspectives on IBD practice, knowledge of IBD management and perceived barriers to care for rural IBD patients.

**Results:** No statistically significant difference was found between rural and metropolitan IBD patients identified on the database. Thirty-three Mount Gambier rural patients returned questionnaires (response rate 30%). No significant difference was found between the Mount Gambier rural cohort and the IBD database metropolitan cohort for the majority of disease complications and outcomes; however variance in medication use and access to imaging was found. A total of 233 healthcare practitioners completed questionnaires (response rate 21%). The majority of rural practitioners felt comfortable with managing IBD, yet 80% of general practitioners felt uncomfortable using immunomodulators. Disease knowledge using a validated tool appeared satisfactory. Teleconferencing and information sessions were suggested as possible interventions to overcome the identified barriers.
Conclusion:

No statistically significant differences in the rate of patient reported disease complications were found. A variance of practice with respect to methotrexate, iron replacement and hydrocortisone therapy and use of MRI was noted. Descriptive data regarding perceived barriers in addition to these findings will help guide future interventions to enable equality of care for patients with IBD living in regional and remote locations.

Keywords

Inflammatory Bowel Disease, Crohn’s Disease, Ulcerative Colitis, Rural Health, Gastroenterology.

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Introduction

Inflammatory Bowel Disease (IBD) is a common disease in western countries\(^1\) and is often associated with high morbidity and a reduction in health related quality of life\(^2\). In Australia around 61,000 people were affected in 2005 and with an increasing prevalence\(^3\) it stands to be a major workload burden for the health care system and a global economic burden. Whilst IBD is reported to be more common in some urban areas\(^4\)-\(^8\), a significant proportion of IBD patients live in rural areas. There is evidence that these patients have to access their care from urban centres, with one such centre reporting that over 40\% of their patients on biological therapies live in rural locations\(^9\).

Because of the complexity of IBD, along with the high morbidity, chronicity and the potential for complications, close and continued collaboration between patients and specialist medical care and other holistic, multi-disciplinary facilities is vital\(^3\). Challenges in obtaining optimal care for patients with IBD are encountered on a day-to-day basis in tertiary centres\(^10\); however, additional distance-related obstacles exist in the rural setting\(^11\), which have the potential to influence disease outcomes.

Despite multiple studies documenting differences in health outcomes and survival rates between rural and urban patients in a number of diseases, minimal published data exists regarding the relative level of disease burden in rural patients with IBD compared to their urban counterparts. There is little known with respect to rural healthcare professionals’ knowledge of and exposure to IBD. Patient and health practitioner perceptions of barriers to optimal care in the rural setting have also not been previously described.
This study therefore aimed to firstly describe the disease burden and treatment experience of IBD in patients living in a rural area as compared to metropolitan locations. We then aimed to identify the level of IBD exposure among rural practitioners and their attitudes to and knowledge of IBD care and to identify any perceived barriers to the care and management of patients in the rural setting compared with their urban counterparts.

Methodology

Overview: This cross-sectional study was conducted in three parts:

- **Firstly**, disease outcomes were compared between IBD patients living in rural as compared to metropolitan locations within an existing IBD database at a metropolitan teaching hospital. To determine whether any possible difference in outcomes might be a reflection of referral bias or real, these data were subsequently compared to a second rural IBD cohort gathered from a clinical database at a large rural General Practice (GP) site.

- **Secondly**, the rural IBD patient cohort (identified via the rural GP practice) was surveyed regarding patient perspectives on the potential barriers to optimal care of rural IBD patients.

- **Finally**, rural healthcare practitioners (HCPs) who care for rural IBD patients and IBD nurses were identified and surveyed regarding their knowledge of and attitude to rural IBD care and their perspectives on the potential barriers to optimal care of rural IBD patients.

**IBD Outcomes**

An existing Southern Adelaide IBD database held at Flinders Medical Centre (FMC) (a 580 bed public teaching hospital servicing the southern population of Adelaide and major regional
rural centres) was reviewed and two cohorts (rural and metropolitan) were obtained. Cohorts were matched for diagnosis, age and gender. Patients on this database had previously consented to participate in IBD research. Disease characteristics and disease outcomes were extracted from a previously completed survey, titled ‘Inflammatory Bowel Disease Survey’ (Appendix 1). Questions related to disease severity, medication use, investigations, surgical interventions and complications.

The second rural IBD GP based cohort was collected from Mount Gambier, South Australia (SA). This location was chosen as it does not have a resident gastroenterologist and is located a significant distance (440km) from the nearest Adelaide tertiary hospital. One large GP practice was contacted and agreed to participate in patient recruitment. Following interrogation of their database, patients with a diagnosis of IBD were identified and invited to participate by completing the same questionnaire as the existing Southern Adelaide patients. Questionnaires were posted accompanied by a letter of invitation, information sheet, consent form and opt-out form. A reminder letter was sent at 2 months except for “return to senders” and opts-out candidates. All completed surveys were de-identified.

**Patient Perspectives**

The IBD cohort from Mount Gambier was asked to complete a second survey titled ‘Perceived barriers to IBD care in the rural setting’. These questions related to their perception(s) of current barriers the optimal care of rural IBD patients (Appendix 2). This survey was identical to Section C of the Rural Practitioner survey (referred to below).
**Rural practitioner IBD exposure and perspectives**

An invitation to participate via completion of a questionnaire was sent out to 1,130 Australian rural surgeons and physicians, SA rural GPs and metropolitan Australian IBD nurses. Rural was defined as practicing in an area with a Rural, Remote and Metropolitan Areas (RRMA) classification\(^{12}\) of 3 or above. Consequently capital cities (RRMA 1) and other metropolitan centres with urban population of >100,000 (RRMA 2) were not included. Australian IBD nurses who are metropolitan based but often involved in assisting in the management of rural patients\(^9\), were identified through their contact list and invited to participate via email. Australian rural surgeons were identified using a list of attendees at the Annual Rural Provincial Surgeons meeting over the last 5 years and contacted via email. Australian rural physicians and SA rural GPs were identified through a Pharmaceutical company’s commercial database Janssen database and were contacted via mail. For all HCPs, if no reply was received, reminder letters were sent after 2 weeks and 2 months. Questionnaires were completed and returned via mail or online.

The questionnaire (Appendix 3) was divided into three sections. Section A sought information regarding IBD exposure and service provision, interest in IBD and attitudes towards current IBD speciality services. Section B examined the level of IBD knowledge (via previously validated questionnaire\(^{13}\)). Section C investigated perceived barriers to optimal care of rural IBD patients. Overall level of rural health care and barriers experienced compared with metropolitan care formed the basis of questions with the final questions relating to suggested solutions. Return of a completed questionnaire was taken as consent.
Data analysis

IBD knowledge and attitudes were compared and assessed using appropriate statistics (Mann-Whitney). The reported perceived barriers to care by rural patients and health care providers were reviewed for common themes within each group.

Ethics approval

The study was approved by the Southern Adelaide Clinical Human Research Ethics Committee.

Results

IBD Outcomes

A review of the FMC IBD database identified 53 rural IBD patients and sixty six metropolitan patients in the comparison cohort. No statistically significant differences were found in disease characteristics or outcomes between cohorts (Table 1).

Interrogation of the Mount Gambier GP practice data base found 114 patients with a diagnosis of IBD. There were 17 opt-outs and 4 return-to-senders. Thirty three people returned the initial disease outcomes survey (response rate 30%) with results outlined in Table 2.

No statistically significant differences were found in disease type, presence and duration of symptoms, extra-intestinal manifestations of IBD, number of hospitalisations or previous surgery between the Mount Gambier rural cohort and metropolitan FMC cohort. The majority of both cohorts had a colonoscopy as part of their diagnostic work up but a statistically significant larger proportion of metropolitan patients had a small bowel x-ray (26/66 vs 3/33
p=0.002) and MRI (19/66 vs 1/33 p=0.003). There was no statistically significant difference in investigation usage throughout the course of their disease. The majority of metropolitan patients (54/66, 82%) were diagnosed by a gastroenterologist, which was significantly higher than the Mount Gambier rural cohort (12/33, 36%). Statistically significant differences were found in medication use in methotrexate (Mount Gambier rural cohort 1/33 3% vs metropolitan FMC cohort 18/66 31% p=0.001) and hydrocortisone (Mount Gambier rural cohort 6/33 (18%) vs metropolitan FMC cohort 35/66 (53%) p=0.001). Furthermore, a greater usage of infliximab was noted in the metropolitan cohort (24/66 36% vs Mount Gambier rural cohort 5/33 15%) although this result was not significant (p=0.036). Whilst no difference was found in incidence of iron deficiency, statistically more metropolitan FMC patients had received oral iron replacement (42/43 98% vs 15/21 71% p=0.004) than Mount Gambier rural patients and a trend was noted for a greater rate of intravenous replacement (FMC metropolitan patients 25/43 58% vs Mount Gambier rural patients 5/21 24% p=0.16).

Patient Perspectives

Of the 114 patients invited to participate (including 17 opt-outs and 4 return-to-senders) 32 people returned the perceived barrier survey (response rate 29%).

Eighty six percent (24/28) of respondents opined that rural IBD patients have worse quality of health compared with people living in metropolitan areas. Perceived barriers to rural IBD care are shown in Figure 1. Access to specialist care was only thought to be adequate by 6/30 (20%) and complications were thought to have been potentially preventable by 14/27 (52%) if access were improved. Communication between the patient’s gastroenterology specialist and primary care physician was felt to be poor in only 1/28, however 8/24 (33%) felt that the level of communication had negatively influenced their outcome(s) in the past. Access to
multidisciplinary team members was reported to be low (specialist colorectal surgeon 9/29, IBD nurse 3/29, dietician 13/29 and psychologist 6/29). Interventions suggested to be most helpful in enhancing access to specialist gastroenterology care are shown in Figure 2.

**Rural HCPs’ IBD exposure and perspectives**

A total of 233 completed questionnaires were obtained from the various HCPs surveyed, with not all participants completing all questions (Figure 3). This achieved an overall response rate of 21%. Demographic details of the cohort are outlined in Table 3.

Whilst the majority of doctors reported being comfortable and happy to manage IBD patients, the level of comfort varied when asked about using different medical therapies (Table 4).

Nearly all GPs and physicians and half of surgeons order blood tests for monitoring patients on immunomodulators. Sixty percent (90/149) of all doctors reported ordering blood tests on a case by case scenario rather than having a formal protocol.

Good communication from gastroenterologists was reported by 18/19 (95%) IBD nurses, 85/112 (76%) GPs, 19/34 (56%) physicians and 23/43 (53%) surgeons. When asked directly what the level the communication between the gastroenterologist and primary care physician was thought to be, 33/109 (30%) of GPs rated it excellent, 73/109 (67%) satisfactory and 3/109 (3%) poor. Several GPs commented that communication was better with private gastroenterologists than from those in the public system.

The level of support from public outpatient departments in relation to IBD was described as good and satisfactory in 30% of GPs (34/112). Opinions regarding personal experience with
public IBD services were varied, whilst approximately half of responding medical practitioners (48/97, 49%) believed that IBD nurses were useful and valuable. A significant proportion of rural doctors however, still preferred to communicate directly with a gastroenterologist (29/53 55% GPs, 7/17 41% physicians and 10/27 37% surgeons).

The majority of participants (100% 20/20 IBD nurses, 78% 91/116 GPs, 52% 23/44 physicians and 80% 35/44 surgeons) were supportive of the idea of IBD action plans. GPs commented that they would be particularly useful for the management of acute flares and suggested that they could be incorporated into GP care plans.

With the use of a previously validated screening tool\textsuperscript{14}, the average correct mean score for IBD knowledge was 8.8/11 for GPs, 9.3/11 for surgeons, 9.8/11 for physicians and 10.4/11 for IBD nurses. When asked directly about participants perceived level of IBD knowledge and training, 71/114 63% of GPs felt that they lacked in this area. This compared with 21/44 48% of surgeons and 10/40 25% of physicians. Of the 71 GPs who felt that they lacked in this area, 34 (48%) reported that this was a barrier to optimal care of this cohort of patients. Workshops, lectures and IBD symposiums focusing on updates in medical management were the most common types of training that were suggested as likely to improve their knowledge.

The majority of participants perceived that outcomes were worse for rural IBD patients compared with their metropolitan counterparts (18/20 90% IBD nurses, 70/96 73% GPs, 23/37 62% physicians and 22/44 50% surgeons). Of those who thought that rural health outcomes for IBD patients were the same in both groups several GPs, physicians and surgeons reported that this was secondary to the presence of a visiting or resident gastroenterologist in their region.
When given a range of options as examples of proposed barriers for optimal IBD care for rural patients 81% of respondents identified distance to specialist services, lack of local multidisciplinary teams and financial costs of accessing specialist services as the three most important barriers to optimal IBD care for rural patients (Figure 1).

The majority of IBD nurses (15/20 75%) reported that access to specialist IBD care was not adequate in rural areas. Rural doctor’s responses were generally evenly divided. Of those who thought that current access was adequate, many reported that they had a visiting or resident gastroenterologist and that access was better in private than in public. Sixty six percent of GPs (63/95) and 78% of physicians (32/41) and surgeons (32/41) felt that some adverse IBD patient health outcomes could have been prevented if access to specialist IBD care was better.

The level of access to members of a multidisciplinary team at the participants practice or within close proximity varied. Half of GPs (53/114, 46%) had direct access to a specialist colorectal surgeon, while 9/115 (8%) GPs had access to an IBD nurse. This was a similar finding among surgeons and physicians. Direct access to a dietician was available by the majority of all doctors (97/115 84% GPs, 38/42 90% physicians and 32/41 78% surgeons), but only 64% physicians (27/42) and surgeons (28/44) had direct access to a psychologist in their region compared with 87/115 (76%) GPs.

Interventions thought to be most helpful in enhancing access to specialist gastroenterology care are shown in Figure 2. Of the doctors who did not list teleconferencing as being helpful, six GPs and two physicians commented that this method was overly time consuming. Others commented that a visiting or resident gastroenterologist in the area would be more helpful.
Discussion

This is the first study to simultaneously describe data regarding disease outcomes of rural IBD patients compared with their urban counterparts, rural practitioner IBD experience and knowledge and perceived barriers to optimal care of rural IBD patients from the perspective of both rural HCPs and patients.

Whilst the majority of our surveyed cohort identified rural IBD patients as having worse healthcare outcomes than their metropolitan counterparts, our data is the first of its kind to report no statistically significant differences in key IBD health outcomes such as disease complications, hospitalisations, surgery and steroid use. Certainly, in other areas of medicine such as cerebrovascular disease, alcohol and smoking rates and rates of hospitalisation and falls, Australians living in regional and remote areas generally have poorer health than those living in major cities\textsuperscript{[14-16]}. These current data is reassuring as despite sentiments from key stakeholders reflecting perceived negative outcomes due to their rural location, the barriers that may exist have not been shown to result in this conclusion. There was, however, variance in clinical practice with respect to methotrexate, iron replacement and hydrocortisone therapy as well as access to small bowel imaging and MRI and access to specialist gastroenterologist for diagnosis.

Tertiary referral centres have noted that a large burden of IBD exists outside of the metropolitan area, with rural patients accessing a substantial portion of metropolitan based services\textsuperscript{[9]}. This was highlighted in an IBD Nurse study which demonstrated that in the 2011 period, non-metropolitan patients represented 498 of the 1211 patients on an IBD data base (41%), and were responsible for 2441 (49.6%) of the occasions of service\textsuperscript{[9]}. Rural areas however, are regions where specialist gastroenterology services are absent and consequently
the majority of long-term care is carried out by rural general practitioners, surgeons and physicians. Despite this, our data show that IBD exposure for individual rural practitioners is marginal with only a small proportion of total practice devoted to this field. Consequently, given the relative lack of exposure to IBD, the risk of deskilling and decline in confidence in managing this cohort in the outpatient setting with the use of various IBD therapies is high. This issue was highlighted by Tan et al who reported 37% of rural and metropolitan GPs in SA were uncomfortable with IBD management and 71% uncomfortable with the use of immunomodulators\(^\text{18}\).

In addition to improving individual primary care physician training, practitioner support from gastroenterologists and specialist services is vital to maintain outpatient care. Whilst access to specialist services appeared be to be satisfactory in regions with resident or visiting gastroenterologists in our study, many regions in rural Australia (and other countries) do not have this luxury.

Despite many rural and remote initiatives over recent years, the health needs of many rural residents, both in Australia and overseas, are still not adequately met. Geographical location (accessibility to and availability of appropriate health services) and rural and remote environments (including socioeconomic status, lifestyles, and indigeneity) are undoubtedly the hallmark characteristics of rural and remote Australia and impact on health outcomes\(^\text{19}\), with the presence of distance being the major impediment to accessing health care. Evidence indicates that there is no one model capable of overcoming identified barriers and servicing the health needs of diverse rural and remote communities, but rather service models must vary in order to take account of the specific geographical, social, economic and cultural contexts that differentiate the many rural and remote communities\(^\text{19}\). Models should also be
guided by the resident medical workforce and community members who are key stakeholders in the care of rural IBD patients, in addition to specialist service providers, which is what our study has endeavoured to do.

Respondents in our study identified teleconferencing and regional information sessions as potential worthwhile interventions in the future designed to overcome these perceived barriers of access and distance to specialised services and associated downfalls of obtaining this (financial cost and lack of personal support systems). Although, telehealth and telemedicine (the real time delivery of health and medical services at a distance between two or more locations using technology-assisted communications) have been widely used in Australia over recent years, evidence to date, shows that the utilisation of this strategy remains patchy\textsuperscript{19} with barriers existing in the domains of time economics (a point shared by a proportion of our respondents) funding priorities, infrastructure, and training\textsuperscript{18}.

Information sessions in region areas was the second intervention supported by our respondents, surprisingly given that this (lack of education) was not highlighted as one of the three most important barriers to care. Additionally, IBD action plans were acknowledged as a potential important tool. There is a near complete absence of IBD action plans available in the literature highlighted by a recent systematic review\textsuperscript{20}, however, coincidentally we have devised an evidence based tool\textsuperscript{21}, which is freely available to download from online IBD support groups and this should be actively promoted.

The strengths of this study consist of the inclusion of opinions from a wide variety of stakeholders and the collection of both quantitative disease outcome data and qualitative participant perspective data, which has not been found in the literature. Each cohort has different roles in the management of rural IBD and consequently their opinions in addition to
patient perspectives and data regarding practitioner exposure to and knowledge of IBD are invaluable. The study is also one of the first to collect data regarding this issue, which is vital to determine if and how interventions may be introduced that would aid in over-coming potential barriers and optimise care of this cohort in the long term.

We wish to acknowledge however, the limitations of the study. Whilst we matched urban IBD patients with rural IBD patients on the tertiary hospital data base, it could well be argued that rural patients who had been seen by the urban tertiary clinic were not representative of all rural IBD patients. The study was also hampered by low response rates from health care professionals and rural IBD patients. The numbers of rural patients recruited to the study may not have been enough to demonstrate variances of outcome between them and their urban counterparts.

In conclusion, our study is the first to compare IBD outcomes between a rural and metropolitan cohort. Whilst reassuringly, there were no significant difference in disease the gross outcomes of complications, hospitalisations, surgery and steroid use between cohorts, variance in clinical practice with respect to methotrexate and iron replacement therapy and access to small bowel imaging and MRI was found, suggesting that care is indeed unequal and that improvements might yield better outcomes. Furthermore, barriers to optimal care have been identified by key stakeholders, which should be viewed as areas for improvement. These data can be used to guide the development of appropriate interventions to enable equality of access and quality of care for patients with IBD living in regional and remote locations.

**NB** – patient questionnaires and documents are located in thesis appendices
References


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<td>12/52 (23%)</td>
<td>18/66 (27%)</td>
<td>0.672</td>
</tr>
<tr>
<td>Ileostomy or colostomy</td>
<td>11/53 (21%)</td>
<td>19/66 (29%)</td>
<td>0.397</td>
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<tr>
<td>Pouch procedure</td>
<td>2/53 (4%)</td>
<td>5/66 (8%)</td>
<td>0.459</td>
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<tr>
<td>Strictureplasty</td>
<td>1/53 (2%)</td>
<td>6/66 (9%)</td>
<td>0.044</td>
</tr>
<tr>
<td>Drainage of abscess</td>
<td>9/53 (17%)</td>
<td>12/66 (18%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Fistulae repair</td>
<td>13/53 (25%)</td>
<td>12/66 (18%)</td>
<td>0.498</td>
</tr>
<tr>
<td>Medication Use (current or past)</td>
<td>47/53 (75%)</td>
<td>57/65 (88%)</td>
<td>1.000</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-------------</td>
<td>-------------</td>
<td>-------</td>
</tr>
<tr>
<td><strong>5 amino-salicylic acid</strong></td>
<td></td>
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<tr>
<td><strong>Immunomodulator</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Azathioprine</td>
<td>28/53 (73%)</td>
<td>45/63 (71%)</td>
<td>0.668</td>
</tr>
<tr>
<td>6MP</td>
<td>8/49 (16%)</td>
<td>7/54 (13%)</td>
<td>0.781</td>
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<tr>
<td>Methotrexate</td>
<td>9/50 (18%)</td>
<td>18/58 (31%)</td>
<td>0.181</td>
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<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Hydrocortisone</td>
<td>29/53 (55%)</td>
<td>35/66 (53%)</td>
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</tr>
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<td>Cyclosporin</td>
<td>3/53 (6%)</td>
<td>8/66 (12%)</td>
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<td>Infliximab</td>
<td>17/53 (32%)</td>
<td>24/66 (36%)</td>
<td>0.670</td>
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<td>Adalimumab</td>
<td>12/53 (19%)</td>
<td>12/66 (17%)</td>
<td>0.647</td>
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<td><strong>Number of steroid courses</strong></td>
<td>3</td>
<td>2</td>
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<tr>
<td><strong>History of Iron deficiency</strong></td>
<td>35/53 (66%)</td>
<td>43/66 (65%)</td>
<td>1.000</td>
</tr>
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<td>Oral replacement</td>
<td>35/35 (100%)</td>
<td>42/43 (98%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Iron infusion</td>
<td>17/35 (49%)</td>
<td>25/43 (58%)</td>
<td>0.495</td>
</tr>
<tr>
<td><strong>Bone densitometry performed</strong></td>
<td>23/52 (44%)</td>
<td>37/66 (56%)</td>
<td>0.026</td>
</tr>
<tr>
<td>Normal</td>
<td>17/23 (74%)</td>
<td>14/37 (39%)</td>
<td>0.009</td>
</tr>
<tr>
<td>Mild osteoporosis</td>
<td>5/23 (22%)</td>
<td>8/37 (22%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Moderate-severe osteoporosis</td>
<td>1/23 (4%)</td>
<td>7/37 (19%)</td>
<td>0.138</td>
</tr>
<tr>
<td>Unsure</td>
<td>2/23 (9%)</td>
<td>8/37 (22%)</td>
<td>0.291</td>
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<tr>
<td><strong>Number of hospitalisations (median)</strong></td>
<td>2</td>
<td>2</td>
<td>0.777</td>
</tr>
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<td><strong>Member of IBD support group</strong></td>
<td>10/53 (19%)</td>
<td>16/66 (24%)</td>
<td>0.512</td>
</tr>
<tr>
<td><strong>Family History of IBD</strong></td>
<td>20/52 (38%)</td>
<td>17/66 (26%)</td>
<td>0.012</td>
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</table>
Table 2. Disease characteristics and outcomes of the rural IBD Mount Gambier cohort and FMC data base metropolitan comparison cohort.

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<tr>
<th></th>
<th>Rural prospective Cohort</th>
<th>IBD data base: Metropolitan Cohort</th>
<th>P value</th>
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<tbody>
<tr>
<td><strong>Type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Crohn’s Disease</td>
<td>18/33 (55%)</td>
<td>39/65 (60%)</td>
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</tr>
<tr>
<td>Ulcerative Colitis</td>
<td>13/33 (39%)</td>
<td>26/65 (40%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Indeterminate colitis</td>
<td>2/33 (6%)</td>
<td>0/65 (0%)</td>
<td>1.000</td>
</tr>
<tr>
<td><strong>Symptom duration before diagnosis</strong> (median) (months)</td>
<td>6</td>
<td>12</td>
<td>0.684</td>
</tr>
<tr>
<td><strong>Extra-intestinal manifestations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Episcleritis</td>
<td>2/33 (6%)</td>
<td>8/66 (12%)</td>
<td>0.489</td>
</tr>
<tr>
<td>Erythema nodosum</td>
<td>2/33 (6%)</td>
<td>6/66 (9%)</td>
<td>0.715</td>
</tr>
<tr>
<td>Spondyloarthropathy</td>
<td>3/33 (9%)</td>
<td>6/66 (9%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Primary sclerosing cholangitis</td>
<td>0/33 (0%)</td>
<td>5/66 (8%)</td>
<td>0.166</td>
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<tr>
<td><strong>Other extra-intestinal manifestations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Addison’s disease</td>
<td>1/33 (3%)</td>
<td>1/66 (2%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Idiopathic thrombocytopenic purpura</td>
<td>1/33 (3%)</td>
<td>2/66 (3%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Polymyalgia rheumatica</td>
<td>2/33 (6%)</td>
<td>3/66 (5%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Alopecia/vitiligo</td>
<td>2/33 (6%)</td>
<td>4/66 (6%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Autoimmune Haemolytic anaemia</td>
<td>0/33 (0%)</td>
<td>3/66 (5%)</td>
<td>0.549</td>
</tr>
<tr>
<td><strong>Weight loss prior to diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18/33 (55%)</td>
<td>31/66 (47%)</td>
<td>1.000</td>
</tr>
<tr>
<td>No</td>
<td>11/33 (33%)</td>
<td>21/66 (32%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Unsure</td>
<td>4/33 (12%)</td>
<td>14/66 (21%)</td>
<td>0.408</td>
</tr>
<tr>
<td><strong>Height increase prior to diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Yes</td>
<td>0/33 (0%)</td>
<td>5/66 (8%)</td>
<td>0.166</td>
</tr>
<tr>
<td>No</td>
<td>8/33 (24%)</td>
<td>11/66 (17%)</td>
<td>0.421</td>
</tr>
<tr>
<td>Unsure</td>
<td>2/33 (6%)</td>
<td>1/66 (2%)</td>
<td>0.257</td>
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<tr>
<td>N/A</td>
<td>23/33(70%)</td>
<td>49/66 (74%)</td>
<td>0.633</td>
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<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
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<tr>
<td>Colonoscopy</td>
<td>23/33 (70%)</td>
<td>59/66 (89%)</td>
<td>0.023</td>
</tr>
<tr>
<td>Flexible sigmoidoscopy</td>
<td>8/33 (24%)</td>
<td>21/66 (32%)</td>
<td>0.490</td>
</tr>
<tr>
<td>Endoscopy</td>
<td>10/33 (30%)</td>
<td>25/66 (42%)</td>
<td>0.510</td>
</tr>
<tr>
<td>CT abdomen</td>
<td>10/33 (30%)</td>
<td>37/66 (56%)</td>
<td>0.019</td>
</tr>
<tr>
<td>Small bowel x-ay</td>
<td>3/33 (9%)</td>
<td>26/66 (39%)</td>
<td>0.002</td>
</tr>
<tr>
<td>MRI</td>
<td>1/33 (3%)</td>
<td>19/66 (29%)</td>
<td>0.003</td>
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<tr>
<td><strong>Practitioner who diagnosed IBD</strong></td>
<td></td>
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<td></td>
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<tr>
<td>Gastroenterologist</td>
<td>12/33 (36%)</td>
<td>54/66 (82%)</td>
<td>0.0001</td>
</tr>
<tr>
<td>GP</td>
<td>8/33 (24%)</td>
<td>4/66 (7%)</td>
<td>0.018</td>
</tr>
<tr>
<td>Surgeon</td>
<td>12/33 (36%)</td>
<td>3/66 (5%)</td>
<td>0.0001</td>
</tr>
<tr>
<td>Other</td>
<td>1/33 (3%)</td>
<td>4/66 (7%)</td>
<td>0.662</td>
</tr>
<tr>
<td><strong>Previous surgery</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ileal resection</td>
<td>7/33 (21%)</td>
<td>13/66 (20%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Duodenal/Jejunal resection</td>
<td>3/33 (9%)</td>
<td>4/66 (6%)</td>
<td>0.683</td>
</tr>
<tr>
<td>Colectomy</td>
<td>5/33 (15%)</td>
<td>18/66 (27%)</td>
<td>0.214</td>
</tr>
<tr>
<td>Ileostomy or colostomy</td>
<td>6/33 (18%)</td>
<td>19/66 (29%)</td>
<td>0.329</td>
</tr>
<tr>
<td>Pouch procedure</td>
<td>3/33 (9%)</td>
<td>5/66 (8%)</td>
<td>1.000</td>
</tr>
<tr>
<td>Strictureplasty</td>
<td>1/33 (3%)</td>
<td>6/66 (9%)</td>
<td>0.419</td>
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<tr>
<td>Drainage of abscess</td>
<td>7/33 (21%)</td>
<td>12/66 (18%)</td>
<td>0.789</td>
</tr>
<tr>
<td>Fistulae repair</td>
<td>10/33 (30%)</td>
<td>12/66 (18%)</td>
<td>0.204</td>
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</table>
### Medication Use (current or past)

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percentage</th>
<th>Comparison</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td><strong>5 amino-salicylic acid</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Azathioprine</td>
<td>17/33</td>
<td>52%</td>
<td>45/63 (71%)</td>
<td>0.070</td>
</tr>
<tr>
<td>6MP</td>
<td>2/33</td>
<td>6%</td>
<td>7/54 (13%)</td>
<td>0.473</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>1/33</td>
<td>3%</td>
<td>18/58 (31%)</td>
<td>0.001</td>
</tr>
<tr>
<td><strong>Immunomodulator</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hydrocortisone</td>
<td>6/33</td>
<td>18%</td>
<td>35/66 (53%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Cyclosporin</td>
<td>0/33</td>
<td>0%</td>
<td>8/66 (12%)</td>
<td>0.049</td>
</tr>
<tr>
<td>Infliximab</td>
<td>5/33</td>
<td>15%</td>
<td>24/66 (36%)</td>
<td>0.036</td>
</tr>
<tr>
<td>Adalimumab</td>
<td>2/33</td>
<td>6%</td>
<td>12/66 (17%)</td>
<td>0.133</td>
</tr>
</tbody>
</table>

| **Number of steroid courses** | 3 | 2 | 0.982 |
| **History of Iron deficiency** | 21/33 (64%) | 43/66 (65%) | 1.000 |
| Oral replacement       | 15/21 (71%) | 42/43 (98%) | 0.004 |
| Iron infusion          | 5/21 (24%) | 25/43 (58%) | 0.016 |

| **Bone densitometry performed** | 17/33 (52%) | 37/66 (56%) | 0.680 |
| Normal                   | 6/17 (35%) | 14/37 (39%) | 1.000 |
| Mild osteoporosis        | 6/17 (35%) | 8/37 (22%) | 0.328 |
| Moderate-severe osteoporosis | 3/17 (18%) | 7/37 (19%) | 1.000 |
| Unsure                   | 0/17 (0%) | 8/37 (22%) | 0.046 |

| **Number of hospitalisations (median)** | 2 | 2 | 0.936 |
| **Member of IBD support group** | 7/31 (23%) | 16/66 (24%) | 1.000 |
| **Family History of IBD** | 9/33 (27%) | 17/66 (26%) | 1.000 |
Table 3. Demographics of IBD nurse and medical practitioner respondents

<table>
<thead>
<tr>
<th>Demographics</th>
<th>GPs (n=118)</th>
<th>Physicians (n=45)</th>
<th>Surgeons (n=48)</th>
<th>IBD Nurse (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>75/117 (64%)</td>
<td>36/42 (86%)</td>
<td>43/47 (91%)</td>
<td>0/22 (0%)</td>
</tr>
<tr>
<td>Female</td>
<td>42/117 (36%)</td>
<td>6/42 (14%)</td>
<td>4/47 (9%)</td>
<td>22/22 (100%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
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<tr>
<td>Years (mean)</td>
<td>48</td>
<td>52</td>
<td>53</td>
<td>48</td>
</tr>
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<td><strong>Training location</strong></td>
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<tr>
<td>Australia</td>
<td>76/101 (75%)</td>
<td>21/38 (55%)</td>
<td>28/48 (58%)</td>
<td>17/22 (77%)</td>
</tr>
<tr>
<td>Overseas</td>
<td>23/101 (23%)</td>
<td>15/38 (39%)</td>
<td>15/48 (31%)</td>
<td>4/22 (18%)</td>
</tr>
<tr>
<td>Both</td>
<td>2/101 (2%)</td>
<td>2/38 (5%)</td>
<td>5/48 (10%)</td>
<td>1/22 (5%)</td>
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<tr>
<td><strong>Year of graduation</strong></td>
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<td>Year (median)</td>
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<td>1985</td>
<td>1981</td>
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<td><strong>Nature of practice</strong></td>
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<tr>
<td>IBD patients (total)</td>
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<td></td>
</tr>
<tr>
<td>&lt;5</td>
<td>68/117 (58%)</td>
<td>14/45 (31%)</td>
<td>20/45 (44%)</td>
<td>0/22 (0%)</td>
</tr>
<tr>
<td>5-10</td>
<td>32/117 (27%)</td>
<td>9/45 (20%)</td>
<td>15/45 (33%)</td>
<td>1/22 (5%)</td>
</tr>
<tr>
<td>10-20</td>
<td>13/117 (11%)</td>
<td>5/45 (11%)</td>
<td>7/45 (16%)</td>
<td>0/22 (0%)</td>
</tr>
<tr>
<td>20-50</td>
<td>4/117 (3%)</td>
<td>12/45 (27%)</td>
<td>3/45 (7%)</td>
<td>0/22 (0%)</td>
</tr>
<tr>
<td>&gt;50</td>
<td>0/117 (0%)</td>
<td>5/45 (11%)</td>
<td>0/45 (0%)</td>
<td>21/22 (95%)</td>
</tr>
<tr>
<td>IBD patients per month</td>
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<tr>
<td>&lt;1</td>
<td>48/117 (41%)</td>
<td>16/45 (36%)</td>
<td>22/46 (48%)</td>
<td>0/21 (0%)</td>
</tr>
<tr>
<td>1-5</td>
<td>65/117 (56%)</td>
<td>13/45 (29%)</td>
<td>21/46 (46%)</td>
<td>1/21 (5%)</td>
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<tr>
<td>5-10</td>
<td>3/117 (2.5%)</td>
<td>8/45 (17.5%)</td>
<td>2/46 (4%)</td>
<td>1/21 (5%)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>1/117 (0.5%)</td>
<td>8/45 (17.5%)</td>
<td>1/46 (2%)</td>
<td>19/21 (90%)</td>
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<td><strong>Location of care</strong></td>
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<tr>
<td>Inpatient</td>
<td>0/115 (0%)</td>
<td>3/40 (8.5%)</td>
<td>3/26 (12%)</td>
<td>0/21 (0%)</td>
</tr>
<tr>
<td>Outpatient</td>
<td>56/115 (49%)</td>
<td>5/40 (12.5%)</td>
<td>0/26 (0%)</td>
<td>5/21 (24%)</td>
</tr>
<tr>
<td>Both</td>
<td>59/115 (51%)</td>
<td>32/40 (80%)</td>
<td>23/26 (88%)</td>
<td>16/21 (76%)</td>
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<tr>
<td><strong>Attitudes to care of IBD patients</strong></td>
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<tr>
<td>Comfortable</td>
<td>73/106 (69%)</td>
<td>23/35 (91%)</td>
<td>26/42 (62%)</td>
<td>21/21 (100%)</td>
</tr>
<tr>
<td>Uncomfortable</td>
<td>33/106 (31%)</td>
<td>3/35 (9%)</td>
<td>16/42 (38%)</td>
<td>0/21 (0%)</td>
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<td><strong>Referral to specialist</strong></td>
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<tr>
<td>Always</td>
<td>58/113 (51%)</td>
<td>6/32 (19%)</td>
<td>18/45 (40%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Often</td>
<td>39/113 (35%)</td>
<td>7/32 (22%)</td>
<td>14/45 (31%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Sometimes</td>
<td>15/113 (13%)</td>
<td>19/32 (59%)</td>
<td>13/45 (29%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Never</td>
<td>1/113 (1%)</td>
<td>0/32 (0%)</td>
<td>0/45 (0%)</td>
<td>N/A</td>
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<tr>
<td>How comfortable are you at initiating/directing/using…? (1 = extremely comfortable to 5 = extremely uncomfortable)</td>
<td>1</td>
<td>2</td>
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<td>Maintenance therapy (agent not specified) (n=117)</td>
<td>24 (20.5%)</td>
<td>37 (31.5%)</td>
<td>26 (22%)</td>
<td>23 (20%)</td>
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<td>Therapy for acute flare (agent not specified) (n=117)</td>
<td>14 (12%)</td>
<td>39 (33%)</td>
<td>30 (26%)</td>
<td>32 (27%)</td>
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<td>Steroids (n=116)</td>
<td>18 (15.5%)</td>
<td>50 (43%)</td>
<td>29 (25%)</td>
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<td>Immunomodulators (n=117)</td>
<td>9 (8%)</td>
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<td>Biologic agents (n=114)</td>
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<td>11 (9.5%)</td>
<td>12 (10.5%)</td>
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Figure 1. Nominated barriers to optimal medical care of rural IBD patients

Figure 2. Proposed interventions to enhance access to specialist Gastroenterology care.
Figure 3. Questionnaires distributed amongst cohorts and those returned.
CHAPTER THREE

TRANSITION INFLAMMATORY BOWEL DISEASE CARE
3.1 Introduction

Abundant literature exists regarding transition care\textsuperscript{27-30}. Little data however, has been published regarding the outcomes of patients with paediatric onset IBD in the years after they have entered adult care or their perspectives on the process. This is important as major changes in transition practices are currently being recommended\textsuperscript{25} without knowing what is actually happening to this group of IBD patients and what is needed. Through this information obstacles in the transition program could be highlighted and potentially guide the development of new and improved programs in the future to optimise patient care.

This chapter includes a manuscript accepted for publication titled “Outcomes and patients’ perspectives of transition from paediatric to adult care in Inflammatory Bowel Disease” which details a project aimed at addressing this issue. It describes the background to the research question, methods used to obtain the data, results and discussion.
# Statement of Authorship

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<th>Title of Paper</th>
<th>Outcomes and patients’ perspectives of transition from paediatric to adult care in Inflammatory Bowel Disease</th>
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## Principal Author

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| Contribution to the Paper                                                                             | (1) conception and design of the study  
(2) acquisition of data  
(3) analysis and interpretation of data  
(4) drafting the article  
(5) revising the article for critically for important intellectual content  
(6) final approval of the version to be submitted |
| Overall percentage (%)                                                                                | 60%                |
| Certification:                                                                                         | This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper. |
| Signature                                                                                             | Date 10.11.2015 |

## Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution

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| Contribution to the Paper | 10%  
(1) revising the article for critically for important intellectual content  
(2) final approval of the version to be submitted  
(3) acquisition of data |
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Outcomes and patients’ perspectives of transition from paediatric to adult care in Inflammatory Bowel Disease

Name of Journal: World Journal of Gastroenterology
Manuscript Type: ORIGINAL ARTICLE - Retrospective Study

Bennett AL et al. Transition care in inflammatory bowel disease

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Abstract

AIM: To describe the disease and psychosocial outcomes of an inflammatory bowel disease (IBD) transition cohort and their perspectives.

METHODS: Patients with IBD, aged > 18 years, who had moved from paediatric to adult care within 10 years were identified through IBD databases at three tertiary hospitals. Participants were surveyed regarding demographic and disease specific data and their perspectives on the transition process. Survey response data were compared to contemporaneously recorded information in paediatric service case notes. Data were compared to a similar age cohort who had never received paediatric IBD care and therefore who had not undergone a transition process.

RESULTS: There were 81 returned surveys from 46 transition and 35 non-transition patients. No statistically significant differences were found in disease burden, disease outcomes or adult roles and responsibilities between cohorts. Despite a high prevalence of mood disturbance (35%), there was a very low usage (5%) of psychological services in both cohorts. In the transition cohort, knowledge of their transition plan was reported by only 25/46 patients and the majority (54%) felt they were not strongly prepared. A high rate (78%) of discussion about work/study plans was recorded prior to transition, but a near complete absence of discussion regarding sex (8%), and other adult issues was recorded. Both cohorts agreed that their preferred method of future transition practices (of the options offered) was a shared clinic appointment with all key stakeholders.
CONCLUSION: Transition did not appear to adversely affect disease or psychosocial outcomes. Current transition care processes could be optimised, with better psychosocial preparation and agreed transition plans.

Key words: Transition care; Crohn’s disease; Ulcerative colitis; Chronic illness; Inflammatory bowel disease; Patient perspectives; Disease outcomes

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INTRODUCTION

In adolescents with chronic diseases, movement from paediatric to adult services is inevitable and is increasingly recognised as an essential element of holistic care\textsuperscript{[1-3]}. A successful transition in young people with chronic conditions differs from simple handover of care and should aim to maximise the young person’s quality of life\textsuperscript{[4]}, with the ultimate goal of facilitating the development of successful self-management\textsuperscript{[5]}.

The topic of transition care has received significant attention in the literature\textsuperscript{[6-9]} with considerable debate around the most effective way to achieve a smooth transition. A general consensus exists however; that whatever solution is adopted it should encompass a comprehensive programme that reflects and encourages the patient’s physical, psychological and social development, rather than merely providing a physical transfer from paediatric to adult care\textsuperscript{[10]}. Implementation of an effective transition program has been shown to improve patient health and life outcomes in patients with liver transplant\textsuperscript{[11]}, diabetes mellitus\textsuperscript{[12]} and juvenile arthritis\textsuperscript{[13]} and facilitate self-reliance\textsuperscript{[14]}. Conversely, if done poorly, adverse effects on health\textsuperscript{[15-17]} and health service use\textsuperscript{[12]} in other diseases have been reported. There is currently only extremely scant outcome data in inflammatory bowel disease (IBD).

In Australia, transition practises for IBD are highly variable and often involve a physical transfer of the patient rather than a coordinated, comprehensive and supportive process. This is despite a recent survey of adult and paediatric gastroenterologists, reporting that this is important\textsuperscript{[18]}.

Previous IBD transition care literature has highlighted multiple barriers to effective transition, with several studies obtaining perspectives from paediatric and adult gastroenterologists’ and
IBD nurses\textsuperscript{[18-21]}. From this growing body of literature practical recommendations for transitioning IBD patients have been promulgated\textsuperscript{[22,23]}. However, as yet, these proposals lack actual outcome data and have omitted patient perspectives. Thus it is not yet clear whether these recommendations would improve health outcomes. Therefore outcome and patient perspective data are needed to critically appraise current practices and inform the development of interventions intended to improve transition outcomes.

The aims of this study were to thus to present such factual data and specifically to describe the disease and psychosocial outcomes and personal perspectives of a cohort of young adults with IBD who had recently moved from paediatric to adult care (transition cohort). The outcomes of this group are also compared to a cohort of patients with IBD with similar demographics and disease duration whose care had been solely in the adult realm (non-transition cohort).

**MATERIALS AND METHODS**

This cross-sectional study was conducted in three parts. Firstly, a cohort of IBD patients diagnosed in paediatric services who had moved to adult care was identified and surveyed. Secondly, the case records of these transition patients were examined to verify their histories and to review clinician recorded data on transition plans and doctor-patient discussions. Finally, a non-transition cohort of young adults with IBD was surveyed for comparison.

Trans\textit{ition Cohort identification and Survey}

In 2013 an IBD database established and maintained at the sole public paediatric gastroenterology service in South Australia (SA), Women’s and Children’s Hospital (WCH), was interrogated to identify people with IBD who had turned 18 (mandatory timing of
transfer of care to adult services) since 2003. Patients diagnosed prior to age 18 on the Royal Adelaide Hospital (RAH) and Flinders Medical Centre (FMC) IBD databases were also identified. Potential participants were invited to participate by completing the questionnaire by return mail. The questionnaire (Appendix 1) included items relating to demographics, disease specific quantitative data, patient perspectives regarding their personal transition experience and perceived barriers.

During this period in SA, transition of adolescent IBD patients to adult healthcare services occurred via a letter of referral and if appropriate, telephone handover. Only since 2013, has IBD and hospital information been sent to the patient and a telephone introductory call by an adult IBD service nurse made.

**Transition cohort medical records review**

In this transition cohort, survey response data were compared to contemporaneously recorded information in paediatric service case notes. Data regarding the planned transition process to adult care, availability of choice of location of adult care, timing of transition, psychosocial discussions during the transition period and disease characteristics at diagnosis were reviewed. Medication recommendations, current medication use, disease complications and surgery following transition to adult care were not reviewed nor confirmed in medical records.

**Non-transition cohort identification and survey**

A comparative cohort who had not undergone transition to adult care was investigated to see whether the transition process itself might have influenced physical/disease and psychosocial outcomes. This cohort was chosen out of a convenience sample of young patients diagnosed
before 18, but never cared for in a paediatric setting. This results from the fact that in SA, from age 14, parents have a choice as to who (paediatric or adult specialist) cares for their child. IBD databases at the RAH and FMC were interrogated to derive a cohort which matched (as closely as possible) the original transition group cohort for age, gender, diagnosis and disease duration. Potential participants were invited to participate by completing the same questionnaire as the transition cohort with exemption of the section relating to personal transition experiences. Given that patients in this cohort did not undergo the transition process, medical records for this group were not reviewed.

Questionnaires were posted out accompanied by a letter of invitation, information sheet, consent form and opt-out form. Both the transition and non-transition cohorts had reminder letters at 2 weeks and 2 months except for “return to senders” and opt-out candidates. All completed surveys were de-identified.

**Ethics, consent and permission:** The study was approved by the Human Research Ethics Committees of the WCH, RAH and FMC. All participating patients completed a consent form.

**RESULTS**

**Survey response**

Two hundred and twenty three transition patients who appeared to have received paediatric IBD care were criteria invited to participate. Twenty-three patients were uncontactable (post marked “return-to-sender”), 49 completed surveys and 8 opted out requesting no further contact (response rate 49/200 = 24.5%). Three of the respondents were subsequently found to
have received all care in the adult setting and were re-allocated to the non-transition cohort, leaving 46 transition respondents. Of 127 non-transition patients invited, 32 completed surveys, 7 opted-out and 6 “return-to-senders” were received (response rate 32/121 = 26%). The 3 surveys earlier excluded from the transition cohort were included in the non-transition cohort, resulting in 35 respondents (Figure 1). Not all respondents answered all questions. Data are presented as a percentage of those answering each item. The response rate did not differ between transition and non-transition cohorts (24.5% vs 26%, \( P = 0.69 \)), and non-responders did not differ from responders in either cohort in terms of age, gender or postcode (as a proxy measure of socioeconomic status).

**Transition and non-transition cohort characteristics**

Amongst transition respondents \((n = 46)\), 31 (67%) had Crohn’s disease (CD), 14 (30%) had ulcerative colitis (UC) and one (2%) had IBD-Unclassified. Compared to case notes data, correct knowledge of disease was found in 100% of patients, however, correct knowledge of disease extent was found in only 18 of 31 patients (58%) with CD and 8/14 (57%) with UC. In the non-transition cohort \((n = 35)\), 22 (63%) had CD and 13 (37%) had UC. Correct knowledge of disease extent was not assessed as case notes for this cohort were not reviewed. Cohorts were matched for age \((P = 0.26)\) and gender \((P = 0.51)\), but a highly statistically significant difference was found between cohorts for disease duration \((P < 0.000005)\). No significant differences were found between cohorts for location of residence or socio-economic status based upon post-code. Demographic details for both cohorts are outlined in Table 1.
**IBD outcomes of transition**

No significant difference was found between cohorts for occurrence of IBD complications (defined as perforation, bowel obstruction or stricture), perianal disease, surgery or hospitalisation since diagnosis (Table 2).

Similar rates of self-reported medication use for most classes of drugs, non-compliance and side effects were found in both cohorts (Table 2). Self-reported medication recommendations compared to actual use was not confirmed given the retrospective nature of the study and the lack of a universal prescription tracking database.

The majority of respondents were regularly reviewed by a gastroenterologist [42/46 (91%), transition patients and 30/35 (86%), non-transition patients]. Among transition patients reviewed 15% were reviewed 3 monthly or more often, 60% 6 monthly and 25% annually. This compared with 38%, 48% and 14% respectively in the non-transition group. Twelve out of 22 (55%) transition patients, all of whom were public patients, reported contacting their IBD nurse as an option if a problem arose and 12 public patients felt adequately supported. Of note, these were not entirely the same 12 who reported contacting the IBD nurses. This compared with approximately the same proportion [12/29 (41%)] non-transition patients contacting their IBD nurse yet almost all [30/31 (97%)] feeling adequately supported.

Utilisation of members of other the multi-disciplinary team was generally low in both cohorts, except for their general practitioners (Table 2). The percentage of physical, psychological and social side effects relating to IBD is outlined in table 2. The most frequent patient-reported symptoms listed in descending order of frequency included; fatigue, weight
loss and diarrhoea; mood disturbance and reduced social interactions and interruptions to work/school.

**Social and occupational outcomes of transition**

No significant differences were seen in the rate of achievement of adult roles and responsibilities (marital status, education level and employment) between patients who transitioned compared to non-transition patients (Table 2).

**Transition experience and perceptions**

Details regarding personal transition experience are outlined in Table 3. Thirty seven (of 46) transition patient medical records were available for review to compare with self-reported plans. In the majority (29/37, 78%) of case notes reviewed, there was evidence of discussion regarding future study/employment; however, documentation of any sexual or psychological discussions was found in only 3 and 7 patients’ files respectively.

Positive feedback regarding what was done well at the time of transition was given by 24 patients (52%) and predominantly centred on provision of information and communication. Conversely, when asked what was done poorly at the time of transition 10/26 (38%) reported ‘Nothing’ and 3 (12%) reported “the handover”. The majority of respondents (37/44, 84%) were currently continuing with the same adult gastroenterologist as initially directed to after transition with no difference observed between those directed to either the public or private medical setting.

The majority (44/46, 96%) of the transition cohort felt that a structured transition plan was important. Non-transition patients also endorsed this statement (32/35, 91%). The transition
cohort identified the task of establishing a new relationship with a practitioner; lack of communication and patients’ own lack of understanding of their disease as potential barriers to successful transition. Similar responses were proposed by the non-transition group. Aspects suggested by respondents as ways of improving the transition process are outlined in Table 3. The majority of transition respondents thought that the timing of transition should be “age 18 years” compared with the non-transition cohort who nominated “patient readiness”. If timing of transition were to be solely based upon age, the transition group identified “age 17-18” whereas the non-transition group said “depended”. When respondents were asked if the timing of transition should be different for males and females, both cohorts replied that it would depend on the scenario. Both cohorts agreed that their preferred method of future transition practices (of the options offered) was that “at the time of transfer there is a single clinic appointment attended by the patient, caregiver, nurse coordinator, paediatric and adult gastroenterologist”.

DISCUSSION

This is the first study to simultaneously describe and compare outcome data and patients’ perspectives with regard to transition, in a cohort of paediatric onset IBD patients who have since moved on to adult care.

Approximately 25% of IBD patients are diagnosed under the age of 16 years[24] with data to suggest that onset in this period can have a more active disease course than in adults[25]. Our data suggests that despite active disease in paediatric years (frequent flares and hospital admissions), the cohort appears to have better disease control after entering adult care. This is represented by an apparent reduction in hospital admissions after leaving paediatric care with a comparable figure to the non-transition cohort. In addition, transition did not appear to
significantly affect the rate of complications, surgery requirements, hospitalisation or perianal disease, which may seem surprising given the longer disease duration in the transition cohort.

Medication use was similar with self-reported non-compliance being low in both cohorts (7% transition, 11% non-transition). This is lower than 35% observed by Lopez San Roman et al.\cite{26} however; it is important to highlight that in reality, when objective measures of adherence were used, it is found that nearly 50% of patients do not take medications as prescribed\cite{27}.

The majority of the transition patients in our cohort appear to be coping well, as assessed by educational activity, employment and partnership rates. These findings are similar to the comparison non-transition cohort and more reassuringly also to Australian Bureau of Statistic population data\cite{28,29} (based upon similar age categories). The only other paper to our knowledge examining these outcomes in young IBD patients found lower rates of further education and employment (50%)\cite{30}, and thus our data is reassuring.

Turunen et al.\cite{31} found that the quality of life of the patients with paediatric onset of IBD was decreased in early adulthood when compared to population-based controls. Our data supports this notion with a significant proportion (35%) reporting mood disturbance but despite this, psychological services are underutilised, with only 5% of those with mood disturbances accessing specific care. Whilst this data is comparable to that of the non-transition cohort suggesting that the transition process itself may not be the sole influence, it is concerning as it represents a lost opportunity to optimise their outcomes entering adult life.
Adult providers have identified a lack of medical knowledge in young patients with IBD transferred from the paediatric clinics\textsuperscript{32}, which may impair the success of transition. Pleasantly, 100\% of patients in both the reported cohorts were able to correctly indicate their diagnosis. However, only 58\% of the transition cohort correctly reported their extent of disease. This ignorance of an important aspect of their disease is in keeping with previous data trends\textsuperscript{32,33}. It is concerning given the potential practical ramifications of preventing effective self-assessment and management. Provision of written information to adolescents, such as an IBD passport\textsuperscript{34}, may alleviate this knowledge gap.

A further area of significant concern is the rare documentation of any discussion regarding sexuality and reproduction on notes review of transitioning patients (in 3/34 notes only). Many young people are sexually active before age 18\textsuperscript{35}, and the lack of early discussion misses an opportunity to inform them accurately about how their IBD and especially any immunosuppressant therapy may or may not affect sexual function, sexually transmitted infections, fertility and pregnancy. This is an area where there is known to be poor knowledge amongst patients and primary care doctors\textsuperscript{36-39}, which can be helped by brief education\textsuperscript{40}. Whilst paediatric gastroenterologists may not feel equipped or comfortable to do this, if they do not start the discussion in may be left until they are sexually active and it may be too late. These issues may have been discussed but not documented, highlighting the need for a transition checklist so that they are indeed addressed perhaps with specific assistance for paediatricians who may not be comfortable with these discussions.

Currently less than half of transition respondents feel that the process they experienced was adequate, with 23\% not feeling prepared and 42\% not feeling part of the decision making process. Whilst approximately half of respondents recalled knowledge of a “transition plan”,
medical records indicate that this was documented in nearly all patients. This suggests that although the idea of transition was discussed 1 year on average prior to actual transition (recorded in notes) it may not be long enough or involve sufficient discussion/documentation to prepare/engage the patient. Future programs may need to involve distribution of written information or use of on-line resources, rather than a simple note in the file, as something to look at away from the doctor’s office.

Our cohort identified aspects of their transition experience that were done well and poorly, pleasingly, these were similar to key concepts of successful transition highlighted in a recent overview of the topic\textsuperscript{[10]}, suggesting clinicians have a good idea of how/where to make changes.

Adolescents with IBD have been highlighted as a group where there are significant barriers to transition to adult care\textsuperscript{[7]}. The barriers identified by patients in our study, in addition to poor patient knowledge, concur with results from a small study of surveyed IBD patients in Spain\textsuperscript{[41]}. Findings differ however, to a medical position paper based upon recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. Barriers discussed related to the reluctance of the patient, their family and medical providers for transition and the lack of a clear and consistent route to follow by medical practitioners\textsuperscript{[42]}. Further survey data obtained from the perspectives of adult and paediatric gastroenterologists and nurses highlights suboptimal training for adult gastroenterologists\textsuperscript{[43]}, lack of entities such as resources, and clinician time\textsuperscript{[20,43]}, and lack of self-advocacy\textsuperscript{[42]} as the main barriers. Perspectives on this topic are diverse and vary according to the cohort surveyed, with a paucity of viewpoints from patient cohorts in published literature. Our study has shown that patient perspectives differ to those aired by healthcare professionals and are
vital, as without them we risk designing a system which suits medical professionals and not patients. Regardless of the origin, barriers identified can potentially lead to sub-optimal outcomes, which have been observed in existing chronic illness programme descriptions\[^{31}\]. Being aware of all barriers is essential to any proposed system re-design to ensure what is done, is practical and acceptable to all stakeholders.

Currently, changes in transition practices are being recommended\[^{7,43,44}\] without knowing what is actually happening to this cohort and what their preferences are. When specifically asked what they would prefer as a transition practice the majority of our transition cohort agreed that a period of overlapping care with a single clinic appointment attended by the patient, caregiver, nurse coordinator, paediatric and adult gastroenterologist would be the most appropriate. This technique has been shown to be beneficial for increasing IBD patients “readiness” for transfer\[^{45}\], and among diabetic patients in improving disease control and increasing rates of follow up\[^{2}\].

Despite the uniqueness of the data collected we recognise the limitations of our study. The foremost is the response rate (about 25%) in both cohorts. These response rates are similar for other young adult cohorts without incentive\[^{46,47}\], and whilst one cannot regard the data as conclusive, one can certainly draw inferences and make suggestions based on this data in conjunction with the scant existing literature. Moreover the data are likely to be representative as there does not appear to be either a strong positive or negative responder bias as no difference in SES, age or gender was found between responders and non-responders. Secondly although the cohorts were matched for age and disease, there was a statistically significant difference in disease duration, despite rigorous attempts to match for this, which may have led to differences in disease outcomes. Responders did not differ in age,
gender or postcode from non-responders so this is somewhat reassuring that there is not a large source of bias. Whilst these limitations exist we feel that our methodology is the most appropriate, as we are documenting outcomes of an existing process before changing it, so any alterations address deficiencies and are in line with patients’ wishes.

Whilst recent transition practice did not appear to adversely affect disease or psychosocial outcomes, current processes could be optimised, with better psychosocial preparation, greater awareness of mood disturbance, more effective provision of psychological care and explicitly documented and shared transition plans. These new data which include young patients’ perspectives are an important missing piece that contributes to a foundation on which future transition practices can be designed to optimise the process and improve outcomes.

NB – patient questionnaires and documents are located in thesis appendices
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8. While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. Good practices that address continuity during transition from child to adult care: synthesis of the evidence. Child: Care,


from the North American Society for Paediatric Gastroenterology, Hepatology, and Nutrition.


Figure 1 Recruitment and patient flow.

- 223 distributed to Transition
  - 200 with correct address
    - 57 replies
      - 49 completed surveys
        - 46 Transition Surveys
  - 23 RTS

- 123 distributed to Non-
  - 121 with correct address
    - 39 replies
      - 32 completed surveys
        - 36 Non-transition
  - 6 RTS

- 8 Opt-outs
- 7 Opt-outs
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<td>4</td>
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<tr>
<td>5</td>
</tr>
</tbody>
</table>

†Australian Standard Geographical Classification – Remoteness Areas; ‡Socio-economic Indexes for Areas - The Index of Relative Socio-economic Advantage and Disadvantage. NB – no statistical difference was found between cohorts for ASGC or SEIFA classification. NB not all subjects answered every question and consequently the denominators for each response are provided.
<table>
<thead>
<tr>
<th><strong>Table 2 Inflammatory bowel disease outcomes of transition</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medication (self-reported)</strong></td>
</tr>
<tr>
<td>5-aminosalicylic acid</td>
</tr>
<tr>
<td>Sulfasalazine</td>
</tr>
<tr>
<td>Mesalazine</td>
</tr>
<tr>
<td>Immunomodulator</td>
</tr>
<tr>
<td>Azathioprine/6</td>
</tr>
<tr>
<td>Mercaptopurine</td>
</tr>
<tr>
<td>Methotrexate</td>
</tr>
<tr>
<td>Biologic therapy (anti-TNF)</td>
</tr>
<tr>
<td>Infliximab</td>
</tr>
<tr>
<td>Adalimumab</td>
</tr>
<tr>
<td>Non-compliance</td>
</tr>
<tr>
<td>Perianal disease</td>
</tr>
<tr>
<td>Complications</td>
</tr>
<tr>
<td>(Perforation, bowel obstruction, stricture)</td>
</tr>
<tr>
<td>Surgery</td>
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<tr>
<td>(Resection +/- stoma, fistula with seton)</td>
</tr>
<tr>
<td>Number of hospital admissions per patient (median)</td>
</tr>
<tr>
<td>During paediatric care</td>
</tr>
<tr>
<td>During adult care</td>
</tr>
<tr>
<td>Number of flares requiring steroids per patient (median)</td>
</tr>
<tr>
<td>Since transition</td>
</tr>
<tr>
<td>During last year</td>
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<tr>
<td>Extra intestinal manifestations of IBD</td>
</tr>
<tr>
<td>(Arthropathy/Cutaneous/Ocular/Hepatobiliary/Metabolic bone disease)*</td>
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<tr>
<td>IBD Symptoms</td>
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<tr>
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<td>Social</td>
</tr>
<tr>
<td>MDT Utilisation</td>
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</tr>
<tr>
<td>Colorectal surgeon</td>
</tr>
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<td>IBD nurse</td>
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<tr>
<td>Married</td>
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<td>Divorced</td>
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<td>Education (level completed)</td>
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<tr>
<td>Secondary</td>
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<tr>
<td>Tertiary</td>
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</table>

84
| TAFE (Technical and further education) | 8/46 (17%) | 12/35 (34%) | 0.12 |
| Apprenticeship/trade                  | 6/46 (13%) | 7/35 (20%)  | 0.54 |
| **Employment**                        |            |             |      |
| Currently employed                    | 35/46 (76%)| 21/35 (60%) | 0.15 |
| Full-time employment                  | 21/35 (60%)| 11/21 (52%) | 0.59 |
| Average hours worked/week             | 29.8       | 34.2        |      |

* Mouth ulcers were omitted
Table 3. Transition experience and perceptions

<table>
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<tr>
<th>Details</th>
<th>Value</th>
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<tr>
<td><strong>Age at first discussion of transition (years)</strong></td>
<td>Median: 18 (Range 16-18)</td>
</tr>
<tr>
<td></td>
<td>Mean: 17</td>
</tr>
<tr>
<td><strong>Age at transition (years)</strong></td>
<td>Median: 18 (Range 16-19)</td>
</tr>
<tr>
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<td>Mean: 18</td>
</tr>
<tr>
<td><strong>Knowledge of transition plan by patient</strong></td>
<td>16/44 (36%)</td>
</tr>
<tr>
<td><strong>Case note documentation of transition plan</strong></td>
<td>32/37 (86%)</td>
</tr>
<tr>
<td><strong>Patient prepared for transition</strong></td>
<td>Not prepared: 10/44 (23%)</td>
</tr>
<tr>
<td></td>
<td>Slightly prepared: 15/44 (34%)</td>
</tr>
<tr>
<td></td>
<td>Strongly prepared: 19/44 (43%)</td>
</tr>
<tr>
<td><strong>Transition felt to be structured</strong></td>
<td>26/41 (63%)</td>
</tr>
<tr>
<td><strong>Part of transition decision making process</strong></td>
<td>25/43 (58%)</td>
</tr>
<tr>
<td><strong>Patient reported choice of transition plan</strong></td>
<td>1/37 (3%)</td>
</tr>
</tbody>
</table>
CHAPTER FOUR

OUTPATIENT INFLAMMATORY BOWEL DISEASE CARE
5.1 Introduction

A considerable proportion of IBD patients have mild to moderate disease and do not need to be seen regularly by a gastroenterologist\textsuperscript{32,33}. The quality of primary healthcare is therefore vital. With the documentation that most GPs do not have a high level of comfort or knowledge of IBD\textsuperscript{14}, educational tools to support primary HCPs is important to optimise outpatient management of UC.

This chapter includes two published manuscripts detailing two projects aimed at addressing this issue.

The first manuscript titled “\textit{Tools for primary care management of inflammatory bowel disease: Do they exist?}” describes a systematic review investigating the availability of non-specialist target educational support tools.

The second manuscript titled “\textit{Ulcerative colitis outpatient management: Development and evaluation of tools to support primary care practitioners}” describes the production and evaluation of evidence-based outpatient management tools for UC to guide primary care practitioners and patients in clinical decision-making. Both manuscripts include an introduction to the research questions, methods used to obtain the data, results and discussion.
# Statement of Authorship

<table>
<thead>
<tr>
<th>Title of Paper</th>
<th>Tools for primary care management of Inflammatory Bowel Disease – do they exist?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Publication Status</td>
<td>✔ Published  □ Accepted for Publication  □ Submitted for Publication □ Publication Style</td>
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## Principal Author

<table>
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<tr>
<th>Name of Principal Author (Candidate)</th>
<th>Alice Bennett</th>
</tr>
</thead>
</table>
| Contribution to the Paper | (1) conception and design of the study  
(2) acquisition of data  
(3) analysis and interpretation of data  
(4) drafting the article  
(5) revising the article for critically for important intellectual content  
(6) final approval of the version to be submitted |
| Overall percentage (%) | 60% |
| Certification: | This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper. |
| Signature | Date 12.10.2015 |

## Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

<table>
<thead>
<tr>
<th>Name of Co-Author</th>
<th>Pia Munkholm</th>
</tr>
</thead>
</table>
| Contribution to the Paper | 15%  
(1) revising the article for critically for important intellectual content  
(2) final approval of the version to be submitted |
| Signature | Date 23.10.2015 |

<table>
<thead>
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<th>Name of Co-Author</th>
<th>Jane Andrews</th>
</tr>
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| Contribution to the Paper | 25%  
(1) conception and design of the study  
(2) analysis and interpretation of data  
(3) revising the article for critically for important intellectual content  
(4) final approval of the version to be submitted |
| Signature | Date 15.10.2015 |
Tools for primary care management of inflammatory bowel disease: Do they exist?

Name of journal: World Journal of Gastroenterology
Manuscript Type: TOPIC HIGHLIGHT

Bennett AL et al. Outpatient Inflammatory Bowel Disease management tools.

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Fax: +61 8 8222 2414
Abstract

Healthcare systems throughout the world continue to face emerging challenges associated with chronic disease management. Due to the likely increase in chronic conditions in the future it is now vital that cooperation and support between specialists, generalists and primary health care physicians is conducted. Inflammatory Bowel Disease (IBD) is one such chronic disease. Despite specialist care being essential, much IBD care could and probably should be delivered in primary care with continued collaboration between all stakeholders. Whilst most primary care physicians only have few patients currently affected by IBD in their caseload, the proportion of patients with IBD-related healthcare issues cared for in the primary care setting appears to be widespread. Data suggests however, that primary care physician’s IBD knowledge and comfort in management is suboptimal. Current treatment guidelines for IBD are helpful but they are not designed for the primary care setting. Few non-expert IBD management tools or guidelines exist compared with those used for other chronic diseases such as asthma and scant data have been published regarding the usefulness of such tools including IBD action plans and associated supportive literature. The purpose of this review is to investigate what non-specialist tools, action plans or guidelines for IBD are published in readily searchable medical literature and compare these to those which exist for other chronic conditions.

Keywords: Inflammatory Bowel Disease, Ulcerative Colitis, Crohn’s Disease, Guidelines, Management tools
INTRODUCTION

Healthcare systems throughout the world continue to face emerging challenges associated with delivering quality, yet affordable, care for chronic disease \[^{[1]}\]. In Australia alone, 77% of citizens reported one or more long-term health problems and more than half of those aged 65 years and older had five or more conditions \[^{[2]}\]. Driven by past achievements in treating and preventing deaths from acute illness, combined with greater longevity, ‘modernization’ of lifestyle and increasing exposure to many risk factors for chronic disease \[^{[3]}\], the number of people with chronic conditions will continue to rise. This changing epidemiology in health care needs is creating a new emphasis on chronic disease management. This requires increasingly complex health care systems and timely and reliable communication, cooperation and support between specialists, generalists and primary health care physicians.

Inflammatory bowel disease (IBD) commonly refers to ulcerative colitis (UC) and Crohn’s disease (CD) and is a complex, relapsing and remitting disorder of the gut and a good example of a chronic condition. Despite specialist care being essential, particularly for the more severe IBD phenotypes, much IBD care could and probably should be delivered in primary care. Certainly in several countries worldwide this is already occurring. However, multi-disciplinary management and continued collaboration between all stakeholders is also crucial to optimal patient outcomes including induction and maintenance of remission and prevention of disease associated complications. Treatment guidelines for IBD, both UC and CD, are clearly outlined by several groups \[^{[4-8]}\] including the European Crohn’s and Colitis Organisation (ECCO) \[^{[9, 10]}\], however, these guidelines are detailed and complex as they are intended to support specialist, referral level practice. Thus, whilst existing guidelines are helpful, they are not designed for the primary care setting. The epidemiology of IBD is such that most primary care physicians only have 2-10 people currently affected by IBD in their
caseload \[^{[11]}\]. Despite the low individual case numbers however, the proportion of patients with IBD-related healthcare issues cared for in the primary care setting appears to be widespread \[^{[12,13]}\]. One study found that general practitioner’s IBD knowledge and comfort in management is suboptimal \[^{[11]}\], yet expecting them to adopt detailed guidelines such as the ECCO ones, is unrealistic.

In other chronic diseases such as asthma, diabetes mellitus (DM) and congestive cardiac failure (CCF), management tools and action plans have been developed to support non-specialist management \[^{[14-16]}\]. However, to our knowledge, few non-expert management tools or guidelines exist for IBD and scant data have been published regarding the usefulness of such tools including IBD action plans and associated supportive literature. Importantly, a Canadian National Physician Survey in 2010 \[^{[17]}\] found that 46% of family physicians use flow sheets and checklists for many conditions, and that more than half of physicians who do not have or use these tools indicated that tools such as these would be beneficial to their practice.

The current study therefore sought to perform a systematic review of the literature to:

1). Investigate what tools, action plans or guidelines for the assessment and management of IBD are published for health professionals other than gastroenterologists (ie non-specialists) in readily searchable published medical literature and

2). Compare what resources are available for IBD to those which exist for other chronic conditions such as asthma, DM and CCF.
METHODS AND MATERIALS

Literature search: A systematic review was performed using PubMed, EMBASE and Ovid Medline databases on May 19 2014 with the following search string: [“Inflammatory Bowel Disease” OR “ulcerative colitis” OR “Crohn’s disease”] AND [“non-specialist” OR “primary care physician” OR “general practitioner” OR “family physician”] AND [“Guidelines” OR “Management” OR “tool”]. When the database allowed we exploded terms to be more inclusive. There was no publication date, publication language or publication status restriction.

This search was then repeated on June 10 2014 with the assistance of an experienced research librarian at the University of Adelaide to ensure no relevant articles were missed. The search was performed on PubMed with the following more detailed search strategy: (((Inflammatory Bowel Diseases [MH] OR Inflammatory Bowel Disease*[TW] OR IBD[TW] OR Ulcerative Colitis[TW] OR Crohn's Disease[TW] OR Crohn Disease[TW])) AND (General Practitioner*[TW] OR GP[TW] OR GPs[TW] OR Physicians, Family [MH] OR Family Physician*[TW] OR Physicians, Primary Care [MH] OR Primary Care Physician*[TW] OR Non-specialist*[TW] OR General practice[MH] OR Family practice[TW])) AND (Practice Guideline [PT] OR Guideline*[TW] OR Manag*[TW] OR Action plan*[TW] OR Tool*[TW])). Titles of all articles were reviewed from both searches and abstracts of those which appeared suitable were read. Articles were selected if they outlined IBD management guidelines or discussed IBD educational tools which provided information regarding assessment and treatment of such patients. These tools were required to be directed at ‘non-specialists’ and not at gastroenterologists.
To compare results between IBD and other chronic medical conditions, the search was repeated on PubMed using the detailed search strategy compiled with the research librarian. The term “IBD” was replaced by “Asthma [MH]”, “Diabetes Mellitus [MH]” and “Congestive Cardiac Failure [MH]”. A further, more specific search was conducted using Ovid Medline with the terms “action plan” AND “Inflammatory Bowel Disease”. This search was then repeated for the same three other chronic diseases. An action plan was defined as a written set of instructions prepared by the doctor that aims to help the patient or their carer recognize worsening of the relevant chronic disease and also then gives clear instructions on what to do in response to this. Articles were only chosen if they had the search term ‘action-plan’ in the title.

RESULTS

**IBD focused literature Searches:**

A total of 630 articles were identified by the initial literature search (Figure 1). Screening by title excluded 627 articles, leaving three articles to review. The repeated search performed with the assistance of a research librarian returned 88 articles. Screening by title excluded 84 articles, leaving 4 articles to review. Three articles had originally been identified in the initial search, leaving one additional article.

A summary of the articles is shown in Table 1. The first two articles \(^{[12, 13]}\) appeared to be ideally suitable for our search; however, the full-text article was not available in English. The remaining two articles \(^{[14, 15]}\) were written in English; however both papers discussed guidelines that were not solely focused on primary physician care. They were based upon guidelines for specialists, surgeons and primary care physicians as opposed to the first two articles where the focus was upon primary care physicians.
Other chronic disorders literature Searches:

In the comparative initial literature searches, a total of 982 asthma, 1709 diabetes, and 406 CCF asthma articles were identified. Screening by title and limiting the search to the past five years resulted in 11, 10 and 7 articles respectively, as shown in Table 2.

“Action plan” literature Searches:

A total of 278 articles were identified from the search when using the search terms ‘asthma’ and ‘action plan’. Fifty relevant articles remained after screening by title. This compared to no relevant articles regarding action plans for IBD, Diabetes Mellitus and CCF remaining after title screen from 1, 49 and 7 articles respectively. Detailed results obtained following the search for action plans are shown in Table 3.

DISCUSSION

Here we show that despite IBD being a worldwide chronic condition with increasing incidence [47, 48], there is a near complete absence in the literature of tools to assist primary care doctors in delivering appropriate, evidence-based care. This is in contrast to the situation for other chronic disorders such as asthma, DM and CCF (diseases with high prevalence rates [49-51]), where such tools are readily found and moreover, at least for asthma, action plans are also easily discovered.

This issue was addressed in a paper by the ECCO Quality of Health Care group, regarding optimization of quality of health care in IBD through one avenue of a consensus of simple guidelines for GP’s [52], and a booklet has been produced by the American Gastroenterology Association outlying IBD patient’s self-management strategies through the use of ‘action plan tools’ [53]. These documents however, were not found through the systematic review
indicating the need for a broader exposure. The articles do however give an evidence base to support the development of the proposed tools in the future.

IBD, both ulcerative colitis (UC) and Crohn’s disease (CD) predominantly have their onset in paediatric or young adult years\(^4\). It is currently observed largely in the developed countries of the world with data showing the highest prevalence values for IBD exist in Europe (UC, 505 per 100,000 persons; CD, 322 per 100,000 persons) and in North America (UC, 249 per 100,000 persons; CD, 319 per 100,000 persons)\(^{54}\). However, the prevalence is rising rapidly in other nations, especially in Asia, as they become more “westernized”\(^{55}\). By 2020, the number of people with CD and UC in Australia alone is projected to increase by 19.6% and 25% respectively \(^{56}\), and this increasing prevalence is being mirrored around the world. Although various phenotypes exist, in both UC and CD, intermittent flares occur, requiring medication adjustments, specialist visits, hospitalizations and also operations with 50-80% of CD patients ultimately requiring surgery for complications such as fistulas, strictures, abscesses and perforations \(^{57}\). Despite this, the vast majority of care occurs in the outpatient setting with various models of care involving primary care physicians, surgeons and gastroenterologists in varying roles, existing.

Two general practitioner studies reported that in a population of IBD patients, between 30% \(^{12}\) and 70% \(^{58}\) of patients were under specialist care. This suggests that a large proportion of people with IBD are predominantly managed in primary care. The majority of patients affected by UC do not require immunomodulator therapy, with 5-aminosalicylic acid (5ASA) formulations proven to be effective for the induction \(^{59}\) and maintenance \(^{60}\) of remission in patients with mildly to moderately active disease. Consequently primary care physicians are
already managing a substantial proportion of IBD (although only a few patients each), so why are there not tools to help them?

A local example of such outpatient care can be taken from two South Australian (SA) tertiary IBD centers at the Royal Adelaide Hospital (RAH) and Flinders Medical Centre (FMC). A recent interrogation of their respective IBD databases revealed 1100 RAH and 1300 FMC patients with IBD. Given that approximately 4,700 people are estimated to have IBD in SA based upon 2005 statistics\textsuperscript{[56]}, approximately 50% are having care either entirely through private specialists or predominantly via primary care physicians, general surgeons and rural physicians. Furthermore, those who are on the IBD databases are often also regularly seen by primary care physicians for minor issues also, especially those located outside of metropolitan regions. Internationally, an English general practice cohort found that in the first 12 months after diagnosis there was a mean (s.d.) of 3.94 (± 3.15) specialist consultations, together with 3.34 (± 3.55) GP consultations specifically related to IBD, and that 55.4% UC and 43.0% of CD patients had been discharged from specialist follow-up\textsuperscript{[12]}. Another UK study showed that about 32% of patients were under the care of a GP alone\textsuperscript{[13]}. Patients appear to receive some or much care at a primary healthcare level and so we need to ensure this care is delivered well.

**Estimate of Indolent and mild IBD courses**

Currently, treatment via primary care doctors would be appropriate for patients with indolent to milder disease courses\textsuperscript{[61, 62]}. These patterns have been evidenced in older epidemiological cohorts from Copenhagen\textsuperscript{[63, 64]} during therapy with 5ASA and steroids and confirmed in Europe when immunological therapy was possible\textsuperscript{[63]}. Calculations were then presented at thesis\textsuperscript{[56]}. The proof that indolent to mild IBD disease exist in larger scale has been
evidenced in unselected cohorts showing that indolent, mild-moderate and severe disease in UC and CD followed in Copenhagen from diagnosis and subsequent 8 years respectively shows 21%, 70% and 9% in UC (Figure 2) and 44%, 36% and 20% in CD (Figure 3). Burisch [63] recently showed in new epidemiologic cohorts in Europe that 15% UC patients versus 9% CD patients run a severe and aggressive course after 1 year with the IBD diagnosis. The indolent to mild cases are ideal for handling predominantly in primary care.

**Specialist care**

As research continues, additional therapeutic agents are entering the realm of IBD management. The choice of therapeutic strategy should be influenced by the activity, distribution, and pattern of disease and the balance between drug potency and side-effect profile; previous response to treatment and the presence of extra-intestinal manifestations [9]. Whilst, for IBD patients with aggressive or refractory disease, highly specialized knowledge and experience are required for providing optimal treatment [65], in community based cohorts, a large proportion of patients with UC never require steroids and nor do many with CD. This cluster would appear to have a milder phenotype and consequently does not necessarily require specialist intervention. For those who do however, this does not preclude their primary care doctors from meaningfully contributing to their care.

Few would argue that IBD patients should be managed without some specialist review or input into their care as data has shown that IBD patients who were treated by an IBD-non specialist are more likely to have uncontrolled diseases status [65]. However, there are a number of ways in which better primary physician care would enhance IBD outcomes, and these practitioners are ideally situated to follow up IBD patients more. If they were also supported by clinical tools, better IBD management is likely to be possible.
Specialist care is often limited by financial costs, waiting times to access specialists, lack of specialist services in region and distance to specialist services. Economically, primary care physicians can provide a more efficient service by being located closer to patients, having reduced fees and being able to address other healthcare issues during standard review. It therefore makes sense to give them tools to support them in providing better IBD care.

**Primary Care physician’s role in shared care of IBD patients**

With evolving therapeutic strategies in the care of IBD patients, evidence now suggests that outcomes are dependent on the quality of management, particularly in early years of diagnosis [66]. Early referral to a gastroenterologist for diagnosis and a structured management plan therefore, is vital [67]. However, referral does not transfer all care of the patient to a specialist and it is recognized now more than ever that shared or multidisciplinary care is the key to achieving optimal health-care outcomes. Opportunities for primary care physicians to promptly recognize IBD relapse and/or acute severe colitis, contribute to other areas of quality IBD care and to reinforce specialist management are listed in Table 4.

**eHealth**

Other techniques to improve the out-patient management of IBD patients have also been investigated. One such strategy has been to focus on improving self-management as this has been demonstrated to improve outcomes of symptoms, psychological well-being, and health-care resource use [67] and to use it as a component of distance management. eHealth telemedicine itself is a form of distance management where patients have the ability to partly self-manage their illness through this technology. Patients are empowered by using eHealth tools. Distance management of IBD has been shown to significantly decrease clinic visit utilization, but at this stage does not significantly affect relapse rates or hospital admission
rates \cite{68}. eHealth internet-based technology is a tool that can be utilized to both promote and enhance gastrointestinal disease management whilst at the same time reduce healthcare costs in IBD \cite{69}. It would seem likely that combining eHealth support for patients’ self-management with tools to support their primary care doctors may synergistically improve non-specialist IBD care.

**Primary physician knowledge and experience with IBD**

This systematic review documents that few tools exist to enhance the knowledge of primary healthcare physicians or non-experts to manage patients with IBD. This may seem surprising given one survey reported 30% of GPs felt uncomfortable managing IBD in general and 71% and 91% were uncomfortable with the use of immunomodulators and biologic agents respectively, whilst more than 70% would appreciate such clinical support tools \cite{11}. A separate survey also reported 71.8% of GPs indicated that they needed better instruction regarding IBD \cite{70}. If primary physician knowledge and experience with IBD is low it may lead to suboptimal management of IBD in the outpatient setting which may lead to consequences such as delayed recognition of acute severe colitis, inappropriate use of steroids, overuse of aminosalicylates in poor responders or delayed intervention in a relapse.

Written actions plans for chronic illnesses have been shown to improve health outcomes. This has been shown in asthma where as part of self-management education, action plans improve health outcomes including hospital admissions, emergency medical contacts, days missed from work, nocturnal asthma symptoms and quality of life in adults \cite{71}. A meta-analysis of self-management in children and adolescents (2-18 years) also showed improved lung function, reduced morbidity and utilization of healthcare resources \cite{72}. Written actions plans have also been found to be acceptable and useful in the setting of COPD \cite{73} and asthma \cite{74}.
In conclusion a gap currently exists in the provision of supportive education tools for primary care practitioners for IBD outpatient care shown by our systematic review, which is in contrast to other chronic diseases. Current levels of non-specialist knowledge and confidence in treating IBD patients has been shown in the past to be suboptimal. A large proportion of IBD care occurs in the outpatient setting and consequently adequate knowledge of the condition and its basic management by primary care physicians is important to improve IBD outcomes and is likely to also be cost effective. Developing tools that address this issue and that are critically appraised by those who will use them, is first step to enhancing this patient care and closing the gap.

NB – patient questionnaires and documents are located in thesis appendices
REFERENCES


2. AIHW. Chronic diseases and associated risk factors in Australia, 2006. Canberra:


Organization practice guidelines for the diagnosis and management of IBD in 2010.


53. Kane S. IBD self-management. The AGA guide to Crohn's disease and ulcerative colitis. 2010 AGA Press. USA.


Figure 1. Literature search
Figure 2. UC disease severity in a Copenhagen cohort. 1157 UD phenotypes, 8 years after diagnosis in an inception cohort 1962 – 1987, Copenhagen. 5ASA and steroids therapy were available\textsuperscript{[64]}.

Figure 3. CD severity in a Copenhagen cohort. 373 CD phenotypes, 8 years after diagnosis in an inception cohort 1962 – 1987, Copenhagen. 5ASA and steroids therapy were available\textsuperscript{[64]}.
Table 1. Article summary

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*Additional article found by supervised search with librarian*
Table 2. Comparison search of educational tools and guidelines for other chronic diseases.

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<td>[On general practitioners' care of patients with asthma]</td>
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<td>An asthma action plan created by physician, educator and patient</td>
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<td>use in primary care [29]</td>
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<td>management according to the GINA 2006-2007 guidelines]</td>
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<td>Summary of the 2008 BTS/SIGN British Guideline on the management of</td>
<td>Levy ML et al</td>
<td>United Kingdom</td>
<td>English</td>
<td>Prim Care Respir J.</td>
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<td>diabetes mellitus</td>
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<td>Insulin management of type 2 diabetes mellitus</td>
<td>Petznick A</td>
<td>United States</td>
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<td>Type 1 diabetes in children - emergency management</td>
<td>Siafarikas A et al</td>
<td>Australia</td>
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<td>Type 2 diabetes: an expanded view of pathophysiology and therapy</td>
<td>Unger J et al</td>
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<td>English</td>
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**Congestive cardiac Failure**

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<td>Echocardiography in heart failure - a guide for general practice</td>
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<td>Australia</td>
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<td>Heart failure management - a team based approach[^44]</td>
<td>Stewart S</td>
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<td>[1st national guideline for chronic heart failure. Essential responsibilities for the family practitioner][^46]</td>
<td>Aumiller J</td>
<td>Germany</td>
<td>German</td>
<td>MMW Fortschr Med.</td>
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Table 3. Articles relating to disease management ‘action plans’.

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Table 4. Health issues potentially addressed by primary care physicians.

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<th>Management of non-IBD related illnesses</th>
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<tbody>
<tr>
<td>Monitoring/treating IBD related complications</td>
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<tr>
<td>a. Osteoporosis</td>
</tr>
<tr>
<td>b. Iron deficiency</td>
</tr>
<tr>
<td>c. Cardiovascular disease</td>
</tr>
<tr>
<td>d. Cancer</td>
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<tr>
<td>Preventative medicine</td>
</tr>
<tr>
<td>a. Vaccinations</td>
</tr>
<tr>
<td>b. Pap smears</td>
</tr>
<tr>
<td>c. Quit smoking</td>
</tr>
<tr>
<td>d. Skin checks (associated non-melanoma skin cancer risk with thiopurine use)</td>
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<tr>
<td>Addressing psychosocial confounding factors</td>
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<tr>
<td>a. Sexual health</td>
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<td>b. Reproductive health</td>
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<tr>
<td>c. Psychological health</td>
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<tr>
<td>Medication compliance</td>
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<td>Prompt recognition of IBD relapse and/or acute severe colitis</td>
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Statement of Authorship

<table>
<thead>
<tr>
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<tr>
<td>Ulcerative colitis outpatient management: Development and evaluation of tools to support primary care practitioners.</td>
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**Principal Author**

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<tr>
<th>Name of Principal Author (Candidate)</th>
<th>Alice Bennett</th>
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<td>(7) conception and design of the study</td>
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**Certification:** This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

**Signature** Date 13.10.2015

**Co-Author Contributions**

By signing the Statement of Authorship, each author certifies that:

iv. the candidate’s stated contribution to the publication is accurate (as detailed above);

v. permission is granted for the candidate to include the publication in the thesis; and

vi. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

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<th>Stephanie Buckton</th>
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NOTE: This publication is included in the print copy of the thesis held in the University of Adelaide Library.

It is also available online to authorised users at:

[http://dx.doi.org/10.1111/imj.12872](http://dx.doi.org/10.1111/imj.12872)
CHAPTER FIVE

DISCUSSION
5.1 Introduction

Patients with IBD can potentially experience physical, social and emotional challenges arising from their chronic gastrointestinal illness. Each IBD cohort encounters generalised and specific issues associated with achieving optimal healthcare outcomes. Data regarding healthcare practices and delivery services are one such issue that has been lacking in the past in the areas of IBD and is discussed in this thesis.

5.2 Specific findings from each project

Below outlines in brief the specific findings of each study.

5.2.1 Rural IBD Care

This study simultaneously describes data regarding patient-reported disease outcomes of rural IBD patients compared with their urban counterparts; rural practitioner IBD exposure and knowledge; and perceived barriers to optimal care of rural IBD patients. Whilst the majority of our surveyed cohort identified rural IBD patients as having worse healthcare outcomes than their metropolitan counterparts, our study found no statistically significant differences in key IBD outcomes of complications, hospitalisations, surgery or delays in diagnosis. Variation in practice with respect to methotrexate, oral iron and hydrocortisone use was found in addition to access and utilisation of imaging. Perspectives on the barriers to optimal care were shared by all cohorts and potential interventions aimed addressing these issues were presented.
5.2.2 Transition IBD Care

This study describes and compares outcome data and patients’ perspectives with regard to transition, in a cohort of paediatric onset IBD patients who have since moved on to adult care. Our data suggests that despite active disease in paediatric years, the cohort appeared to have better disease control after entering adult care. In addition, transition did not appear to significantly affect the rate of patient-reported complications, surgery requirements, hospitalisation or perianal disease nor did it negatively impact on adult roles including educational activity, employment and partnership rates. Whilst recent transition practice did not appear to adversely affect disease or psychosocial outcomes, current processes could be optimised, with better psychosocial preparation, greater awareness of mood disturbance, more effective provision of psychological care and explicitly documented and shared transition plans.

5.2.3 Outpatient IBD Care

These studies highlight the near complete absence in the literature of tools to assist primary care doctors in delivering appropriate, evidence-based care. This is in contrast to the situation for other chronic disorders such as asthma, diabetes mellitus and congestive cardiac failure where such tools are readily found and moreover, at least for asthma, action plans are also easily discovered.

The second study described the development and evaluation of three educational guides for non-specialist and primary healthcare practitioners to support safe, evidence-based outpatient management of UC in addition to providing a UC action plan.
5.3 Over-riding discussion

This thesis presents outcome data and perspectives on IBD care in two large cohorts of IBD patients. In recent years recommendations have been made regarding changes to current healthcare practices, without data to know what is actually happening to these cohorts, what is required and what the perspectives are from those who are involved in these areas. Such ill-informed change has the potential to be inefficient, ineffective and harmful.

Reassuringly, this thesis suggests there are no concerning statistically significant differences in cohorts relating to rural location or transition from paediatric to adult care. This is encouraging however it is at odds with current patient and practitioner perspectives. Whilst this is the main finding of the research, and one may propose that interventions to change current practices are not needed, data obtained from the studies suggests that healthcare practices in these areas could be optimised.

Various areas of potential for improvement were highlighted in patient and practitioner perspectives and also reported outcomes. These include access to multidisciplinary teams, psychological support, improved communication among all major parties involved and disease education for patients. In conjunction with reporting this data, suggestions for future healthcare practices in these areas were offered and comments encouraged for additional ideas. This relevant qualitative data is invaluable to ensure any implemented process is accepted and valued by those involved. More importantly, it is evident that perspectives differ according to which cohort (HCPs, gastroenterologists, patients) is surveyed. Patient perspectives, for which this thesis provides, are certainly vital as without them we risk designing a system which suits medical professionals and not patients.
Whilst, rural and transition IBD care are areas of unique circumstances, all IBD patients will require outpatient management of their chronic disease. This thesis identifies a near absence of freely available IBD educational supportive tools and action plans for primary HCPs who are at the forefront of outpatient care. Timely intervention and proactive management is ideal to optimise the care of people with UC in the community. With evidence to suggest that a significant proportion of GPs are uncomfortable in general with IBD and with many commonly used IBD therapies support guidelines are invaluable.

Having highlighted this deficiency, the thesis proceeds to describe the development and evaluation of educational resources, designed to support non-specialists, optimise outpatient management and educate and empower IBD patients. Feasibility testing insured that the documents were repeatedly critically appraised, by all major stakeholders prior to dissemination. Data showed that there were minimal safety concerns and the majority of surveyed practitioners felt that the documents would improve IBD management. The documents are now freely available to download by anyone worldwide at an online IBD support group (referenced in the manuscript) and are hosted within Australian versions of GP software: Medical Director and Best Practice.

Trends in physical and psychosocial outcomes with comparison to matched cohorts in addition to key stakeholder perspectives regarding IBD care and practices are vital to critically appraise our current practise. Furthermore, this data will aid in the development of interventions that could potentially overcome obstacles in an effort to further optimise patient care. Designing interventions which are not required or not perceived as welcomed by patients would be inefficient. Therefore, with limited healthcare resources, qualitative and quantitative data to inform service delivery are essential prior to making any
recommendations or changes to current practice. Provision of supportive, educational tools for non-specialist practitioners is just one step in the process of optimising key areas in IBD care.

5.4 Research limitations

Despite the uniqueness of the data collected in all three areas, limitations of the studies exist. The foremost is the low response rate in all cohorts surveyed. This was despite reminder letters being sent to cohorts at several intervals after the initial invitation. Ethics approval did not permit contacting the candidates by any other method. The response rates seen are however, similar for other adult cohorts without incentive\textsuperscript{39,40}. Whilst one cannot regard the data as conclusive, one can certainly draw inferences and make suggestions based on this data in conjunction with the scant existing literature. Moreover the data are likely to be representative as there does not appear to be either a strong positive or negative responder bias as no difference in age or gender was found between responders and non-responders.

Secondly, the data collected was primarily patient-reported outcomes in the rural and transition cohorts and thus inherently subjective and quantitative. Whilst this poses a risk of responder/recall bias, the data still remains equally as important as qualitative data as discussed by Greenhalg et al\textsuperscript{41}.

Thirdly, the projects did not research how barriers identified in the three areas of IBD care actually influenced disease and psychosocial outcomes; however this was beyond the scope of the projects.
5.5 Future directions

The thesis provides a starting point for understanding the barriers encountered in three key aspects of IBD care. Whilst this data is vital to begin to comprehend what limitations exist to obtaining optimal healthcare outcomes, further research is required in each area. Furthermore, strategies to overcome the identified areas of concern and timely implementation are required.

5.5.1 Rural IBD Care

The findings of this study are at odds with patient perspectives and one may question whether this was as a result of the methodology not allowing these findings to be detected or that perceptions do in fact not match with reality. Future research therefore, should include prospective collection of patient-reported and disease outcomes to ascertain whether this is a true finding.

Further research is also required to determine whether variations in IBD practice in relation to medication and imaging use are due to lack of practitioner awareness and education or an alternative cause. If lack of education is the causative factor, supportive tools, such as those developed in the Outpatient IBD care project, would be beneficial.

Despite no statistically significant differences in patient reported disease outcomes being found between cohorts, many respondents aired concern of several key limitations in achieving ideal health care for rural IBD patients. In conjunction with this data, future interventions need to be developed and implemented to address and overcome some of these real and perceived issues. The 2 most favoured interventions found were information sessions for patients and primary HCP and teleconferencing between gastroenterologist, the patient
and the primary HCP. Future work may include pilot programs that include these interventions with prospectively collected patient-reported and disease outcomes and patient and HCP perspective qualitative data. One could then truly evaluate whether these interventions improved rural IBD care.

5.5.2 Transition IBD Care

Similarly to the Rural IBD Care project, the study findings were at variance with patient perspectives. Consequently, prospectively collected data including patient-reported and disease outcomes would allow researchers to ascertain whether there is a true difference.

Further research is required to investigate the high prevalence of mood disorder in adolescent and paediatric cohorts noted in our study and the reasons behind underutilisation of psychological services. This finding is concerning as it represents a lost opportunity to optimise their outcomes entering adult life. Future work could include implementing a psychology service at both paediatric and adult outpatient services where the patient is required to attend an initial visit and follow-up appointment if no alarm features are identified. If identified as ‘at risk’ then the patient could be linked into regular reviews. Prospectively collected data regarding whether or not this makes a positive impact on these outcomes could be achieved.

The thesis suggested a lack of medical knowledge in young patients with IBD represented by more than half of patients correctly reporting their extent of disease. This is concerning given the potential practical ramifications of preventing effective self-assessment and management. Provision of written information to adolescents may alleviate this knowledge gap and could
be an area for future work and a study testing knowledge before and after provision of information could ascertain whether this was effective.

Whilst the transition practice did not appear to adversely affect disease or psychosocial outcomes, the thesis highlighted that current processes could be optimised. In addition to improving psychological care and patient education, other areas for future work include explicitly documented and shared transition plans, improved communication and development and implementation of a new transition process where the initial review is attended by all involved practitioners, and IBD nurse the patient and their family. A comparison cohort after interventions have been implemented for some time could be asked to complete the same questionnaire to see if this has achieved an improvement in current disease and psychosocial outcomes.

5.5.3 Outpatient IBD Care

The evidenced based educational tools were launched in 2014. Consequently, future directions of this study would involve testing whether the documents improved outpatient management.

With regards to the UC action plan this may involve a control trial where UC patients are given the action plan for a period of time and disease outcomes including presentation to primary HCPs and tertiary centres are recorded and matched to a UC population who continue with standard care. Qualitative data regarding the usefulness of the document from primary HCPs and patients after a period of use would also be vital.
With regards to the other supportive tools qualitative data gathered from primary care physicians after a period of use would be informative to see if the documents subjectively improved their management of IBD. Objectively, one could review prospectively collected tertiary hospital admission and outpatient data over several years to see if disease outcomes varied after all documents were implemented.
CONCLUSION
6.1 Conclusion

In conclusion, IBD is a complex chronic disease with many differing cohorts of patients. These cohorts require unique and tailored healthcare practices in order to achieve optimal health outcomes. In this thesis, vital missing data relating to three specific cohorts of IBD patients were obtained and presented. This data, both qualitative and quantitative, suggests that current practices in the care of transition and rural IBD patients is not resulting outcomes compared to their counterparts. It has however, illustrated certain aspects of rural, transition and outpatient IBD care that are deficient and provided the perspectives from key stakeholders (gastroenterologists, primary HCPs, IBD nurses and IBD patients) regarding these issues. This data may form the foundation of future research and assist design and implementation of interventions and healthcare policies, aimed at optimising health outcomes in these areas.
References


28. Hait E, Arnold JH, Fishman LN. Educate, communicate, anticipate-practical recommendations for transitioning adolescents with IBD to adult health care. Inflamm Bowel Dis. 2006;12(1): 70–73.


Appendices

Appendix 1: Rural IBD Care Documents

Southern Adelaide Clinical Human Research Ethics Committee
Southern Adelaide Health Service

09 January 2013

Dear Dr Bennett

This is a formal correspondence from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC). Whilst this official title of the committee has changed the committee is still properly constituted under AHEC requirements with the registration number EC00100. This committee operates in accordance with the “National Statement on Ethical Conduct in Human Research” by this department only uses email correspondence for all documents unless prior arrangements have been made with the manager.

Application Numbers: 365a.12

Title: Rural patients with Inflammatory Bowel Disease (IBD) – burden of disease and perceived barriers to treatment

Chief Investigator: Dr Alice Bennett

The Issues: The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) have reviewed and approved the above application. Your project may now commence. The approval extends to the following documents/channels:

- Low and negligible risk application dated 19 December 2012
- Letter from Professor Robert Fraser Head of Gastroenterology and Hepatology at Flinders Medical Centre dated 13 November 2012
- Letter of approval from Associate Professor Matthias Wichmann in the department of surgery at The Mount Gambier Hospital dated 08 January 2013
- Introduction and Attitudes among surgeons to Inflammatory Bowel Disease survey
- Introduction and Care of rural patients with Inflammatory Bowel Disease survey
- Introduction and Perceived barriers to Inflammatory Bowel Disease (IBD) care in the rural setting survey
- Proposed schedule for contacting participants
- Consent form to Participate
- Inflammatory bowel disease survey - CONFIDENTIAL

Approval Period: 09 January 2013 to 08 January 2016

Please retain a copy of this approval for your records.
Research Project Information Sheet

Rural patients with Inflammatory Bowel Disease (IBD) – burden of disease and perceived barriers to treatment.

Dr Alice Bennett, Gastroenterology Advanced Trainee
Associate Professor Peter Bampton, Head of Luminal Gastroenterology, Flinders Medical Centre
Associate Professor Jane Andrews, Head IBD Service & Education, Royal Adelaide Hospital
Associate Professor Matthias Wichmann, General Surgeon, Mount Gambier Hospital

My name is Alice Bennett and I am a senior Gastroenterology Registrar. As part of my Inflammatory Bowel Disease Fellowship year in 2015 I am completing a research project together with my consultants A/Professor Peter Bampton and A/Professor Jane Andrews, at Flinders Medical Centre and A/Professor Matthias Wichmann, a Mount Gambier General Surgeon. The project aims to examine rural patients with Inflammatory Bowel Disease (IBD), their burden of disease and perceived barriers to treatment.

Despite literature documenting disadvantaged healthcare and consequently worse health outcomes in some rural communities compared with those residing in urban regions, little published data exists regarding the level of disease burden in rural patients with IBD. Additionally, limited knowledge regarding patient and rural practitioner perspectives on the barriers to optimal medical care exists.

Given that you have IBD and reside in a rural area, your participation in two surveys would provide valuable information regarding these issues and thus would be greatly appreciated. The initial questionnaire aims to identify your views on any perceived barriers to the care and management of patients with IBD in the rural setting compared with their urban counterparts. The second survey aims to obtain information regarding your IBD (medications used, complications etc). This information will then be compared with information from patients with IBD that live in metropolitan areas to highlight any differences.

The questionnaires will require approximately 15 minutes to complete and are strictly voluntary. If you choose to participate in the study you would require your consent on the attached form and ask that you return this form together with the completed questionnaire in the reply paid envelope provided. The questionnaires have been given ethics approval by Southern Adelaide Clinical Human Research Ethics Committee, in order to ensure that all information will remain confidential please do not include your name. The data will be stored at Flinders Medical Centre at a secure site in locked cabinets.

Thank you for taking the time to assist with this research project. The data collected will provide vital information regarding the possible barriers to rural IBD patients care and may subsequently guide the development of multi-disciplinary interventions/strategies which could be introduced in the rural setting to enhance patient outcomes.

If you require any further information or have questions, please contact me at the number listed below.

Dr Alice Bennett
Gastroenterology Fellow
Flinders Medical Centre
Phone: 8204 5450
alice.bennett@health.sa.gov.au

A. Professor Peter Bampton
Head of Luminal Gastroenterology
Flinders Medical Centre

A. Professor Jane Andrews
Head Inflammatory Bowel Disease
Royal Adelaide Hospital

175
Dear Participant,

My name is Alice Bennett and I am a senior Gastroenterology Registrar. As a part of my Inflammatory Bowel Disease Fellowship year in 2013 I am completing a research project together with my consultants Assoc. Professor Peter Bampton and Assoc. Professor Jane Andrews, at Flinders Medical Centre. The project aims to examine rural patients with Inflammatory Bowel Disease (IBD), their burden of disease and perceived barriers to treatment.

Despite literature documenting disadvantaged healthcare and consequently worse health outcomes in some rural communities compared with those residing in urban regions with respect to various diseases, little published data exists regarding the level of disease burden in rural patients with IBD. Additionally, limited knowledge regarding patient and rural practitioner perspectives on the barriers to optimal medical care exists.

Given that you may be involved in the care of rural patients with IBD, your participation in this survey would provide valuable information regarding these issues and thus would be greatly appreciated. The questionnaire aims to identify your level of exposure to and clinical experience with IBD patients, and any perceived barriers to the care and management of patients with IBD in the rural setting compared with their urban counterparts.

The questionnaire will require approximately 20 minutes to complete and is strictly voluntary. The questionnaire has been given ethics approval by Southern Adelaide Clinical Human Research Ethics Committee. In order to ensure that all information will remain confidential, please do not include your name. The data will be stored at Flinders Medical Centre at a secure site in locked compacts.

If you choose to participate in the study please return the questionnaire in the envelope provided or alternatively complete the questionnaire online by going to the website: https://www.surveymonkey.com/s/RuralIBD.

Thank you for taking the time to assist with this research project. The data collected will provide vital information regarding the possible barriers to rural IBD patients care and may subsequently guide the development of multi-disciplinary interventions/strategies which could be introduced in the rural setting to enhance patient outcomes.

If you require any further information or have questions, please contact me at the number listed below.

Kind regards,

Dr Alice Bennett
Gastroenterology Fellow
Flinders Medical Centre
Phone: 8204 5450
alice.bennett@health.sa.gov.au

A. Professor Peter Bampton
Head of Luminal Gastroenterology
Flinders Medical Centre

A. Professor Jane Andrews
Head Inflammatory Bowel Disease
Royal Adelaide Hospital
Rural Practitioner Survey: Care of rural patients with Inflammatory Bowel Disease

Section A

1. Demographics (fill in)
   - Age:
   - Gender:
   - Year graduated:
   - Type of specialist (please circle):
     o Rural General practitioner
     o Rural Surgeon
     o Rural Physician
     o Gastroenterologist
     o IBD Nurse
   - Australian trained/overseas trained:
   - Postcode of practice:

2. Nature of IBD practice (please circle):
   - Approximately how many IBD patients do you currently care for? (total):
     - <5
     - 5-10
     - 10-20
     - 20-50
     - >50
   - Approximately how many IBD patients do you see per month:
     - <1
     - 1-5
     - 5-10
     - >10
   - Type of IBD do you treat:
     - Crohn’s disease
     - Ulcerative colitis
     - Both
   - What type of IBD care do you provide?
     - Inpatient
     - Outpatient
     - Both
   - If you are a gastroenterologist, what proportion of the total number of IBD patients that you care for reside in a rural area?
     - < 25%
     - 25-50%
     - 50-75%
     - > 75%

3. Attitudes to IBD (Please circle if relevant)
   - Comfortable (happy to manage)/Uncomfortable (difficult to manage)?
   - Referral to gastroenterologist: never / sometimes / often / always
   - Refer preferentially to: private sector / public sector / depends on patient insurance?

4. Treatment (rate 1-5: 1 = extremely comfortable; 5 = extremely uncomfortable)
   - How comfortable are you in initiating/directly using:
     - Maintenance therapy
     - Therapy for acute flare
     - Steroids
     - Immunomodulants (azathioprine, 6-MP, MTX)
     - Biologics (Infliximab, Humira)
• What is your practice with monitoring patients on immunomodulators:
  - Do you do routine blood counts? Y N
  - How often? – weekly / monthly / 3-monthly / on advice from gastroenterologist
    1. Who checks these?
    2. Is there a formal protocol for this or decided case-by-case?
    Please explain:

5. Communication from Gastroenterologist (Please circle all that apply if relevant)
   • Good, clear Poor other (please describe):
   • Frequent/prompt slow
   • Supportive unclear

6. How would you describe the support from Public hospital outpatients?

7. Views on IBD service (if relevant)
   • Previous experience?
   • IBD nurse: useful, valuable / prefer to communicate with gastroenterologist?

8. Would you find individual IBD patient action plans useful? (circle)
   • Yes No Not sure Please explain:

Section B – IBD knowledge

TRUE or FALSE? Please circle either TRUE, FALSE or UNSURE in response to each of these statements:

1. Inflammatory bowel disease can spread to others (ie it is contagious).
   TRUE FALSE UNSURE
2. Inflammatory bowel disease can cause bowel cancer.
   TRUE FALSE UNSURE
3. Children of IBD patients have an increased risk of developing inflammatory bowel disease.
   TRUE FALSE UNSURE
4. The spouse/partner of a patient with IBD has an increased risk of developing inflammatory bowel disease.
   TRUE FALSE UNSURE
5. Some people with inflammatory bowel disease eventually need bowel surgery.
   TRUE FALSE UNSURE
6. Smoking can make Crohn’s disease worse.
   TRUE FALSE UNSURE
7. Smoking can make ulcerative colitis worse.
   TRUE FALSE UNSURE
8. People with inflammatory bowel disease are not allowed to eat dairy products.
   TRUE FALSE UNSURE
9. Inflammatory bowel disease runs in families.
   TRUE FALSE UNSURE
10. Patients with inflammatory bowel disease are probably cured if they have been symptoms free for 3 years.
    TRUE FALSE UNSURE
11. Patients with inflammatory bowel disease can get inflammation in other parts of the body as well as the bowel.
    TRUE FALSE UNSURE

Section C

1. Do you think that rural IBD patients have the same health outcomes as compared with their metropolitan counterparts?
- Yes
- No
- Why or why not?

2. What are the THREE most import barriers to optimal IBD care for rural patients? (please circle)
   - Lack of investigation and treatment facilities in local region
   - Distance to specialist services
   - Separation from personal support systems when accessing services away from local region
   - Financial costs of accessing specialist facilities
   - Lack of IBD education for rural primary care providers
   - Lack of IBD education in patients
   - Lack of IBD nurse coordinators in rural areas
   - Inability to access specialist (gastroenterologist) advice by primary care providers
   - Lack of multi-disciplinary teams (including dietician, psychologist, IBD nurse) in rural setting

3. Do you think patient access to specialist IBD care is currently adequate?
   - Yes
   - No
   - Please explain

4. Do you feel that some adverse IBD patient outcomes could have been prevented if access to specialist IBD care was better?
   - Yes
   - No
   - Please explain

5. Do you think that communication between the gastroenterologist specialist and primary care physician is:
   - Excellent
   - Satisfactory
   - Poor
   - Has this impacted on your patient outcomes in the past?

6. At your practice or within close proximity, do you have access to the following members of a multidisciplinary team?
   - Specialist colorectal surgeon: Y/N
     - If not near you, by phone/email?
   - Nurse practitioner/coordinator: Y/N
     - If not near you, by phone/email?
   - Dietician: Y/N
     - If not near you, by phone/email?
   - Psychologist: Y/N
     - If not near you, by phone/email?

7. Do you feel that you have adequate knowledge/training in the care of IBD patients?
   - Yes
   - No
   a. If not, do you feel this is a barrier to optimal care of this cohort of patients? Please explain
   b. What type of IBD training would benefit you?

8. Would any of the following interventions aimed at enhancing access to specialist gastroenterologist care be helpful to you? Please circle
   - Teleconference (between primary care physician, patient and gastroenterologist)
   - Teleconference (between patient and gastroenterologist)
   - Availability of emailing Gastroenterologist by patient
   - Availability of emailing IBD Nurse coordinator by patient
   - Information sessions for patients and their family held in the local region by IBD coordinator and specialist (yearly)
   - If you would not find these helpful, why not?

9. What else do you think could be done in the rural IBD care setting to overcome barriers to your IBD care?
Rural Patient Survey: Perceived barriers to Inflammatory Bowel Disease (IBD) care in the rural setting

1. Do you think that rural IBD patients have the same quality of health compared with people living in metropolitan areas?
   - Yes
   - No
   - Why or why not?

2. What do you feel are the THREE most important barriers to optimal IBD care for rural patients? (please circle)
   - Lack of investigation and treatment facilities in local region
   - Distance to specialist services
   - Separation from personal support systems when accessing services away from local region
   - Financial costs of accessing specialist facilities
   - Lack of IBD education for rural primary care providers (ie GPs, local surgeons, nurses)
   - Lack of IBD education for patients
   - Lack of IBD nurse coordinators in rural areas
   - Inability to access specialist (gastroenterologist) advice by primary care providers
   - Lack of multi-disciplinary teams (including dietician, psychologist, IBD nurse) in rural setting

3. Do you think patient access to specialist IBD care where you live (specialist gastroenterologists, IBD nurses, dieticians etc) is adequate?
   - Yes
   - No
   - Please explain

4. If you have ever had any complications associated with your IBD, do you feel that they could have been prevented if access to specialist IBD care was better?
   - Yes
   - No
   Please explain

5. Do you think that communication between the gastroenterologist specialist and primary care physician (GP) is:
   - Excellent
   - Satisfactory
   - Poor

   Has the level of communication affected you or your health with regards to IBD in the past?
   - Yes
   - No
   If so please explain

6. Do you have access to any of the following members of a multidisciplinary team? (circle all available to you)
   - Specialist colorectal surgeon: Y N If not near you, by phone/email?
   - Nurse practitioner/coordinator: Y N If not near you, by phone/email?
   - Dietician: Y N If not near you, by phone/email?
   - Psychologist: Y N If not near you, by phone/email?

7. Do you feel that your primary care physician (GP) has had adequate knowledge/training in the care of IBD patients?
   - Yes
   - No
   a. If not, do you feel this is a barrier to your optimal IBD care?
8. Would any of the following interventions aimed at enhancing access to specialist gastroenterologist care be helpful to you? (Please circle)
- Teleconference (between primary care physician, patient and gastroenterologist)
- Teleconference (between patient and gastroenterologist)
- Availability of emailing Gastroenterologist by patient
- Availability of emailing IBD Nurse coordinator by patient
- Information sessions for patients and their family held in the local region by IBD coordinator and specialist (yearly)

If you would not find these helpful, why not?

9. What else do you think could be done in the rural IBD care setting to overcome barriers to your IBD care?
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INFLAMMATORY BOWEL DISEASE SURVEY

How to complete this survey

INSTRUCTIONS:

• This survey contains questions relating to your inflammatory bowel disease (IBD).
• The first sections of the survey contain questions about your condition just before you were diagnosed with inflammatory bowel disease and around the time of your diagnosis.
• Later on there are some questions that are more relevant to patients who have been diagnosed with inflammatory bowel disease for more than 12 months.
• Please use a black/blue pen or pencil.
• To answer each question, you just need to tick the appropriate response box.
• Please erase or correct mistakes.
• There is room on the last page to write down any comments or suggestions you have about the survey.

If you have any questions or need help filling in this survey please contact:
Peta Leach on 08 8204 3942 / email peta.leach@fmcsa.sa.gov.au
or Ruth Prosser on 08 8204 5402 / ruth.prosser@fmcsa.sa.gov.au

Thank-you for your help with this important research.
Section A.
First we would like you to think back to the time before and around the time that you were diagnosed with inflammatory bowel disease.

1 How long did you have symptoms before your inflammatory bowel disease diagnosis was made? (Please write down)
   __________ days or __________ weeks or __________ months or __________ years

2 What symptoms did you experience BEFORE and/or AFTER you were diagnosed with inflammatory bowel disease? (Please tick appropriate boxes on each line. If you did not experience the symptom, please tick the NO box).

<table>
<thead>
<tr>
<th>Symptom Description</th>
<th>6 months or more before diagnosis</th>
<th>During the 6 months before diagnosis</th>
<th>After diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>a Abdominal or stomach pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b Diarrhoea (including diarrhoea at night)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c Constipation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d Blood in stools</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e Lethargy (lacking energy)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f Recurrent mouth ulcers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g Weight loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h Other (please write in the box below)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 3. Were you diagnosed with any of the following conditions BEFORE and/or AFTER you were diagnosed with inflammatory bowel disease?

(Please tick appropriate boxes on each line. If you were not diagnosed with any of those conditions, please tick the NO box.)

<table>
<thead>
<tr>
<th>Condition</th>
<th>6 months or more before diagnosis</th>
<th>During the 6 months before diagnosis</th>
<th>After diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Episcleritis/iritis/uveitis (Red inflamed eyes with increased sensitivity to light; treated with steroid eye drops or tablets)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>b Erythema nodosum (painful red swelling or lumps usually over legs; treated with steroids)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>c Pyoderma gangrenosum (ulceration on the skin, usually the legs; treated with steroids)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>d Spondyloarthropathy (a condition that affects the joints of the lower spine, hips and knees. Advanced stages may result in a stooped posture)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>e Primary sclerosing cholangitis (chronic liver disease that affects the bile ducts. It occurs when the body's immune system starts to attack itself)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

### 4. Did your weight increase between the onset of your symptoms and your inflammatory bowel disease diagnosis?

<table>
<thead>
<tr>
<th>No</th>
<th>Not sure</th>
<th>Yes</th>
<th>By how much?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>kilograms or</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>pounds</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>I don't know</td>
</tr>
</tbody>
</table>

### 5. Did your weight decrease between the onset of your symptoms and your inflammatory bowel disease diagnosis?

<table>
<thead>
<tr>
<th>No</th>
<th>Not sure</th>
<th>Yes</th>
<th>By how much?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>kilograms or</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>pounds</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>I don't know</td>
</tr>
</tbody>
</table>

---

This question is for patients diagnosed with inflammatory bowel disease before 18 years of age.

### 6. Between the onset of symptoms and your inflammatory bowel disease diagnosis, did you grow taller?

(Please tick one box only N/A – Not Applicable)

<table>
<thead>
<tr>
<th>N/A</th>
<th>No</th>
<th>Not sure</th>
<th>Yes</th>
<th>By how much?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>centimetres or</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>inches</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>I don't know</td>
</tr>
</tbody>
</table>
Section B.
Next we would like to ask you some general questions about your inflammatory bowel disease at the time of your diagnosis.

<table>
<thead>
<tr>
<th>7</th>
<th>What type of inflammatory bowel disease were you diagnosed with?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>Crohn's Disease</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b</td>
<td>Ulcerative Colitis</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c</td>
<td>Indeterminate Colitis</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

8 On what date was your inflammatory bowel disease diagnosis made? (If you are not sure of the exact date, please write down the year if you can.)

_______ day ________ month ________ year

9 Who diagnosed your inflammatory bowel disease? (Please tick one box on each line)

<table>
<thead>
<tr>
<th>a</th>
<th>Gastroenterologist (Gut specialist)</th>
<th>Yes</th>
<th>No</th>
<th>Name and location of the doctor</th>
</tr>
</thead>
<tbody>
<tr>
<td>b</td>
<td>Surgeon</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Other medical specialist</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>d</td>
<td>General Practitioner</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>e</td>
<td>Other</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What tests did you have to confirm your diagnosis? (Please tick one box on each line)</td>
<td>No</td>
<td>Yes</td>
<td>Name of the hospital or day surgery clinic</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------------</td>
<td>----</td>
<td>-----</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>a</td>
<td>Colonoscopy (Tube inserted into the rectum to examine the large bowel)</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>Flexible sigmoidoscopy (Sometimes called a short colonoscopy. Tube inserted into the rectum to examine the lower 20-30cm of the large bowel)</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Endoscopy (Tube inserted into the mouth to examine the stomach and small bowel)</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>d</td>
<td>Small bowel x-ray (For example barium meal, barium study)</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>e</td>
<td>CT scan of the abdomen (special type of x-ray)</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>f</td>
<td>MRI scan of the abdomen (special type of x-ray)</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>g</td>
<td>Other (Please write down)</td>
<td>□</td>
<td>□</td>
<td></td>
</tr>
</tbody>
</table>

11 How much did you weigh at the time of your diagnosis? (Please write down)

[Space for writing] kilograms or stone pounds or □ I don’t know

12 What was your height at the time of your diagnosis? (Please write down)

[Space for writing] centimetres or feet inches or □ I don’t know

13 Please write down the name and address of the local doctor (General Practitioner) you had around the time you were diagnosed with inflammatory bowel disease.
(For example Dr Smith, Sunn Road, Maton)

[Space for writing]

14 Please write down the name and address of your CURRENT local doctor (General Practitioner).
(For example Dr Smith, Sunn Road, Maton)
(If this doctor is the same as in Question 13, please write ‘same’)

[Space for writing]

15 Have you EVER joined an inflammatory bowel disease support group?

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

189
Section C.
We would now like to ask if anyone in your family has been diagnosed with inflammatory bowel disease.

16 Do you have a family history of inflammatory bowel disease (including Crohn's disease, Ulcerative colitis, Indeterminate colitis)?
By family history we mean your mother, father, brothers, sisters, children, grandparents, aunts, uncles, nieces, nephews, cousins)
(Please tick one box only)

<table>
<thead>
<tr>
<th></th>
<th>Not to my knowledge (Please go to Section D on the next page)</th>
<th>No (Please go to Section D on the next page)</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17 Please write down the type of relative/s and the type of inflammatory bowel disease they have been diagnosed with.

<table>
<thead>
<tr>
<th>Relative</th>
<th>Disease they were diagnosed with</th>
</tr>
</thead>
<tbody>
<tr>
<td>For example</td>
<td>For example</td>
</tr>
<tr>
<td>Uncle (father's side)</td>
<td>Crohn's disease</td>
</tr>
<tr>
<td>Grandmother (mother's side)</td>
<td>Ulcerative colitis</td>
</tr>
<tr>
<td>a</td>
<td></td>
</tr>
<tr>
<td>b</td>
<td></td>
</tr>
<tr>
<td>c</td>
<td></td>
</tr>
<tr>
<td>d</td>
<td></td>
</tr>
<tr>
<td>e</td>
<td></td>
</tr>
<tr>
<td>f</td>
<td></td>
</tr>
</tbody>
</table>

Section D.
Now we would like to ask you some questions about surgical procedures that you may have had for inflammatory bowel disease.

18 Have you had any of the following surgical procedures for inflammatory bowel disease? (Please tick one box on each line) If yes, please write down the year and hospital where the surgery was carried out.

<table>
<thead>
<tr>
<th>Procedure Description</th>
<th>No</th>
<th>Yes</th>
<th>Year when the surgery was carried out</th>
<th>Hospital and/or day surgery clinic where the surgery was carried out</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Ileal Resection (may include a right hemicolectomy) (<em>cutting out</em> the lower end</td>
<td></td>
<td></td>
<td>First</td>
<td>First</td>
</tr>
<tr>
<td>portion of the small intestine and/or a small part of the right colon)</td>
<td></td>
<td></td>
<td>Second</td>
<td>Second</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Third</td>
<td>Third</td>
</tr>
<tr>
<td>b. Duodenal or Jejunal Resection (<em>cutting out</em> the 1st or 2nd portion of the small</td>
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<tr>
<td>intestine)</td>
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<td></td>
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<tr>
<td>c. Colectomy (removal of all or part of large intestine, called the colon)</td>
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</tr>
<tr>
<td>d. Ileostomy or Colostomy (a &quot;bag&quot; or a stoma – requiring a bag attached to the skin</td>
<td></td>
<td></td>
<td>First</td>
<td>First</td>
</tr>
<tr>
<td>to be worn to collect waste)</td>
<td></td>
<td></td>
<td>Second</td>
<td>Second</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Third</td>
<td>Third</td>
</tr>
<tr>
<td>e. Pouch Procedure (J or W) (Formation of an internal pouch from the small bowel,</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>in the shape of a J or W)</td>
<td></td>
<td></td>
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<tr>
<td>f. Strictureoplasty (opening up a narrowing in the bowel)</td>
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<td></td>
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<tr>
<td>g. Draining of abscesses (perianal and/or abdominal) (Drainage of pus from an</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>inflamed area around the back passage or from inside the abdomen)</td>
<td></td>
<td></td>
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</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. Repair of Fistula (A fistula is an abnormal connection that develops between the</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>inner surface of the bowel and other parts of the body such as the bladder and the</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>outer surface of the skin)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Section E.
Now we would like to ask you some questions about medications you have taken for inflammatory bowel disease.

#### 10 Have you EVER had any of the following medications for your inflammatory bowel disease?

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>No</th>
<th>Yes</th>
<th>Year Started</th>
<th>Duration (Number of weeks)</th>
<th>Maximum Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>Salazopyrin (Sulfasalazine)</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>Dipentum (Olsalazine)</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Socolax (Tablet/enema/foam)</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d</td>
<td>Pentasa (Tablet/suppository/enema)</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e</td>
<td>Mesasa (Mesalazine)</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f</td>
<td>Balsalazide (Colazide)</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g</td>
<td>Predsol (enema/suppository)</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h</td>
<td>Trial drug for inflammatory bowel disease (Please write down the name)</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 20 Did you have a reaction to any of the medications listed in Q19? (Please tick at least one box on each line)

<table>
<thead>
<tr>
<th></th>
<th>No Reaction</th>
<th>Rash</th>
<th>Nausea and/or Vomiting</th>
<th>Diarrhea and/or Dietary problems</th>
<th>Other (Please write down)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>Salazopyrin (Sulfasalazine)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b</td>
<td>Dipentum (Olsalazine)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c</td>
<td>Socolax (Oral/enema/foam)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d</td>
<td>Pentasa (Oral/suppository/enema)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e</td>
<td>Mesasa (Mesalazine)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f</td>
<td>Balsalazide (Colazide)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>g</td>
<td>Predsol (Enema/suppository)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>h</td>
<td>Trial drug for inflammatory bowel disease (Please write down the name)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

---

192
21. Have you EVER had any of the following immunosuppressants (immunomodulating medications) for your inflammatory bowel disease?  

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>Year started</th>
<th>Duration (Number of weeks)</th>
<th>Maximum Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. Azathioprine (Imuran)  
b. 8MP (Mercaptopurine/Pur-nethol)  
c. Methotrexate

22. Did you have a reaction to any of the immunosuppressants (immunomodulating medications) listed in Question 21? (Please tick at least one box on each line)  

<table>
<thead>
<tr>
<th></th>
<th>Never Taken</th>
<th>No Reaction</th>
<th>Rash</th>
<th>Nausea and/or Vomiting</th>
<th>Painful Joints</th>
<th>Pain in the abdomen</th>
<th>Liver problems</th>
<th>Other (please specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. Azathioprine (Imuran)  
b. 8MP (Mercaptopurine/Pur-nethol)  
c. Methotrexate

23. Approximately, how many courses of PREDNISONE (steroid tablets) have you taken for inflammatory bowel disease? (Prednisone is also known as Prednisolone, Prednizone). (A course is defined as the time taken from starting Prednisone until you are weaned off and eventually stop taking Prednisone altogether)  

_______ courses

24. Have you EVER been given intravenous medication for your condition? (through a drip in your hand or arm) (Please tick one box on each line)  

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>Number of times</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a. Hydrocortisone (steroid)  
b. Cyclosporine  
c. Infliximab (Remicade)
Section F.
We would now like to ask you a few questions about rare conditions that may occur together with inflammatory bowel disease.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Year of Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you EVER been diagnosed and treated for any of the following rare conditions that may occur together with inflammatory bowel disease? (Please tick one box on each line)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Addison’s Disease (Destruction of the adrenal gland)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Idiopathic Thrombocytopenic Purpura (Bruise easily due to low platelets in blood. Treated by steroids, removal of spleen and immunosuppression)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Polymyalgia Rheumatica (Severe aching and stiffness in the neck, treated with steroids)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Alopecia or Vitiligo (Alopecia: Patchy hair loss affecting hair bearing area. Vitiligo: Abnormal white patches on the skin, face, neck, and scalp)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Autoimmune Haemolytic Anaemia. (The increased destruction of red blood cells)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26 Have you EVER been told that you had iron deficiency or that you were anaemic? (Please tick one box only)</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27 Have you EVER been treated with iron supplements? (Please tick one box only)</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28 Have you EVER been given iron as an infusion through a drip? (Please tick one box only)</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29 Have you EVER been screened for Osteoporosis by checking your bone density? (Please tick one box only)</td>
<td>No (Please go to Q32)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 Where was the bone density testing performed? (For example usually at an X-ray clinic or hospital) (Please write down)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31 What were the results of the bone density testing? (The results are written in the report given to your doctor) (Please tick one box only)</td>
<td>Normal</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mild bone thinning (Osteoporosis)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Moderate to severe bone thinning (Osteoporosis)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you were diagnosed less than 12 months ago, you have now reached the end of the survey. Please turn to the back page to provide comments if you wish.
**Section G.**

Now we would like to ask you some questions about follow-up tests and procedures that some patients may have had since their original diagnostic investigations. This is not relevant to you if you were diagnosed within the last 12 months.

### 32 Since you were first diagnosed with inflammatory bowel disease have you had any of the following medical investigations for your inflammatory bowel disease?

(Please tick one box on each line.)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Number of Times</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>c</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>d</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>e</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**33 Approximately, how many times have you been admitted to hospital as an inpatient for inflammatory bowel disease?**

(Please do not include outpatient visits) (Please write down)

__________

**34 Approximately, how many times have you had bowel surgery for your inflammatory bowel disease?**

(This includes removal of part of the bowel, or drainage of abscesses or surgery for fistulae) (Please write down)

__________

**35 Please think of your three most recent hospital visits for inflammatory bowel disease. Please write down the name of the hospital and the length of your stay**

<table>
<thead>
<tr>
<th></th>
<th>Name of hospital</th>
<th>Length of stay (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>Hospital visit 1 (Most recent)</td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>Hospital visit 2</td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Hospital visit 3</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2: Transition IBD Care documents

10th January 2013

Dr Alice Bennett
IBD Service, Q7
Dept of Gastroenterology and Hepatology
Royal Adelaide Hospital
NORTH TERRACE SA 5000

Dear Dr Bennett

Re: Outcomes of patients with paediatric onset Inflammatory Bowel Disease following transition into adult care — what do we know? REC2510/11/2012 (LRR — HREC/12/WCHN/169)

I refer to your email dated 27th December 2012 in which you responded to matters raised by the WCHN Human Research Ethics Committee at its November 2012 meeting. I am pleased to advise that your protocol has been granted full ethics approval and meets the requirements of the National Statement on Ethical Conduct in Human Research.

This letter constitutes advice on ethical consideration only. You must not commence this research project at the WCHN or any other SA Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained through a Site Specific Assessment (SSA) request. For information on this process at the WCHN, please contact the WCHN Research Governance Officer, Ms Angelika Lipinski (telephone 6194 6066, email angelika.lipinski@health.sa.gov.au).

I remind you approval is given subject to:

• immediate notification of any serious or unexpected adverse events to subjects;
• immediate notification of any unforeseen events that might affect continued ethical acceptability of the project;
• submission of any proposed changes to the original protocol. Changes must be approved by the Committee before they are implemented;
• immediate advice, giving reasons, if the protocol is discontinued before its completion;
• submission of an annual report on the progress of the study, and a final report when it is completed. Please note it is your responsibility to provide these reports — without reminder from the Ethics Committee.

Approval is given for three years only. If the study is more prolonged than this, an extension request should be submitted unless there are significant modifications, in which case a new submission may be required. Please note the approval number above indicates the month and year in which approval expires and it should be used in any future communication. If University of Adelaide personnel are involved in this project, you, as chief investigator must submit a Human Research Approval notification form online at http://www.adelaide.edu.au/ethics/human/guidelines/ within 14 days of receiving this ethical clearance to ensure compliance with University requirements and appropriate indemnification.

Yours sincerely

PETER ANDERSON (APROF)
CHAIR
WCHN HUMAN RESEARCH ETHICS COMMITTEE
06 May 2013

Dear Dr. Bennett,

This is a formal correspondence from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC). Whilst this official title of the committee has changed the committee is still properly constituted under AHEC requirements with the registration number EC0188. This committee operates in accordance with the "National Statement on Ethical Conduct in Human Research (2007)." This department only uses small correspondence for all documents unless prior arrangements have been made with the manager.

Application Number: 195.13

Title: Outcomes of patients with paediatric onset Inflammatory Bowel Disease following transition into adult care – what do we know?

Chief Investigator: Dr. Alice Bennett

The Issue: The Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) have reviewed and approved the above application. Your project may now commence. The approval extends to the following documents/changes:

- Low and negligible risk application dated 09 April 2013.
- Patient Information sheet and consent form dated 09 April 2013.
- Proposed schedule for contacting participant.
- OPT-OUT FORM dated 09 April 2013.
- Questionnaire for patients with paediatric onset Inflammatory Bowel Disease that have since transitioned to adult care dated 09 April 2013.
- Letter of support from Professor Robert Fraser, Director of Gastroenterology and Hepatology at Flinders Medical Centre dated 05 April 2013.
- Approval letter from Associate Professor Peter Anderson at the Woman’s and Children’s Research Ethics Committee dated 10 January 2013.

Approval Period: 06 May 2013 to 05 May 2014

Please retain a copy of this approval for your records.
Dear Dr Bennett,

Project title: Outcomes of patients with paediatric onset Inflammatory Bowel Disease following transition into adult care – what do we know?

Re: Ethics Application Approval – RAH Site

I am pleased to advise that Royal Adelaide Hospital Research Ethics Committee APPROVAL is granted to the following reviewed documents in relation to the above project, for RAH purposes:

- RAH Information Sheet
- RAH Letter of Invitation
- RAH Reminder Letter

This approval is conditional to the appropriate approval from Governance for your initial application.

Research Ethics Committee deliberations are guided by the NHMRC National Statement on Ethical Conduct in Human Research 2007.

RAH GENERAL TERMS AND CONDITIONS OF ETHICAL APPROVAL:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.

- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
  
  (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
  
  (b) changes to the protocol,
  
  (c) premature termination of the study,
  
  (d) a study completion report within 3 months of the project completion.

- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.

Yours sincerely,

Dr A Thornton
CHAIRMAN
RESEARCH ETHICS COMMITTEE
RESEARCH PROJECT INFORMATION SHEET

Name of study: Outcomes of patients with paediatric onset Inflammatory Bowel Disease following transition into adult care – what do we know?

Principal Investigator: Dr Alice Bennett
Co-Investigators: Dr David Moore, A/Prof Jane Andrews

Introduction

This is a research study to gather information about health outcomes of patients with Inflammatory Bowel Disease. Being part of this study may or may not have any benefits for you. You will only be included in this study if you agree to participate.

Details about this study are discussed below. It is important that you take the time to read this document carefully and understand the information in order to decide if you want to participate.

1. **What is the purpose of the study?**

We believe it is important to find out what has happened to children with IBD after they leave paediatric care and enter adult medicine, as these are life-long diseases, and little is known about disease progress and behaviour once people such as yourself, leave paediatric care. At present, major changes in transition practices (arrangements for sending you from paediatric to adult medical services) are being recommended without knowing what has actually happened to people such as you with IBD and what is needed from your point of view. Therefore our study, through the use of a questionnaire, aims to identify the health outcomes (physical, social and psychological) of this cohort of people, including yourself, and to obtain your experiences and perceptions of the transition process.

2. **Who is eligible and how many people will be involved in the study?**

To be eligible to participate in the study you must:
- Be aged >18yrs at the time of enrolment
- Be diagnosed with IBD (Crohn's disease or Ulcerative colitis) before the age of 18yrs

Approximately 200 young adults in South Australia will potentially be involved in the study.

3. **What does the study involve?**

Your identification. The Women's and Children's Hospital IBD database was accessed by WCHN staff in order to assess your eligibility. This letter was sent out by WCHN staff.

Initially, I invite you to participate in the study by returning the enclosed questionnaire and consent form. If you would prefer to complete the questionnaire by phone or email please indicate this and include your contact details when returning the consent form. If you provide other contact details, I will then confirm consent with you either via email or verbally before proceeding with the questionnaire. If you do not wish to participate in the study, you may indicate this by completing and returning the 'opt out' form. No further contact will be attempted upon receiving this form.

If after 2 weeks I have not received a reply, a reminder letter will be posted to you and again at 3 months.
The study will involve completion of a questionnaire. The questions will be divided into four sections:

- Section A: questions relating to general demographic details (age, postcode, education level etc)
- Section B: questions relating to your IBD (current disease activity, disease complications, medical and surgical treatment history and future management etc)
- Section C: questions relating to your transition experience (age of transition etc)
- Section D: questions relating to the perceived barriers to transition

The questionnaire will take approximately 50 minutes to complete and can be returned via email or in the reply envelope.

We ask that you do not include your name on the returned questionnaire.

4. If I take part in this research study, how will my privacy be protected?

Personal data, including your name and address, from the database has been collected by a WCHN staff member and will remain confidential. If you consent to participate in the study, we ask that you do not put your name on the questionnaire as the data from the study will remain ‘de-identified’. Information/data from this study may be published in academic journals or discussed at academic meetings, and your personal details will remain confidential.

If you choose to participate, your WCH medical records will be accessed to obtain information about your diagnosis, investigations that you had and your follow-up whilst at the WCH. This information is important for the study.

The data will be stored at the Royal Adelaide Hospital at a secure site in locked compacts for 15 years.

5. Who should I contact if I have questions?

If you have any questions about the study please contact Dr Alice Bennett, Principal Investigator. Contact details below.

6. Ethical approval for this study

The study has been given ethical approval by the WCHN Human Research Ethics Committee and RAH Human Research Ethics Committee. If you wish to discuss the approval process or have any concerns or complaints please feel free to contact the Executive Officer of the Committee, Ms Brenda Penny 08 8161 0521.

Research contact details:

Primary Investigator: Dr Alice Bennett
Gastroenterology Fellow
Level 07
Department of Gastroenterology
Royal Adelaide Hospital
North Terrace, Adelaide 5000
alice.bennett@health.sa.gov.au
0428830979
RESEARCH PROJECT INFORMATION SHEET

Name of study: Outcomes of patients with paediatric onset Inflammatory Bowel Disease following transition into adult care – what do we know?

Principal Investigator: Dr Alice Bennett
Co-Investigators: Dr David Moore, A/Prof Jane Andrews

Introduction

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Details about this study are discussed below. It is important that you take the time to read this document carefully and understand the information in order to decide if you want to participate.

1. What is the purpose of the study?

We believe it is important to find out what has happened to children with IBD after they leave paediatric care and enter adult medicine, as these are life-long diseases, and little is known about disease progress and behaviour once people such as yourself leave paediatric care. At present, major changes in transition practices (arrangements for sending you from paediatric to adult medical services) are being recommended without knowing what has actually happened to people such as you with IBD and what is needed from your point of view. Therefore our study, through the use of a questionnaire, aims to identify the health outcomes (physical, social and psychosocial) of this cohort of people, including yourself, and to obtain your experiences and perceptions of the transition process.

2. Who is eligible and how many people will be involved in the study?

To be eligible to participate in the study you must:
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Approximately 200 young adults in South Australia will potentially be involved in the study.

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Your identification: The Women’s and Children’s Hospital IBD database was accessed by WCHN staff in order to assess your eligibility. This letter was sent out by WCHN staff.

Initially, I invite you to participate in the study by returning the enclosed questionnaire and consent form. If you would prefer to complete the questionnaire by phone or email please indicate this and include your contact details when returning the consent form. If you provide other contact details, I will then confirm consent with you either via email or verbally before proceeding with the questionnaire. I will then send the questionnaire to you via the preferred avenue or arrange a phone interview at a convenient time.

If you do not wish to participate in the study you may indicate this by completing and returning the ‘opt-out’ form. No further contact will be attempted upon receiving this form.

If after 2 weeks I have not received a reply a reminder letter will be posted to you and again at 2 months.
If you consent to participate in the study, we ask that you do not put your name on the questionnaire as the data from the study will remain ‘de-identified’. Information/data from this study may be published in academic journals or discussed at academic meetings, and your personal details will remain confidential.

The data will be stored confidentially, at the Royal Adelaide Hospital at a secure site in locked compacts for 15 years.

5. Are there any risks if I participate?

The study involves completion of three short questionnaires relating to the usefulness of three IBD tools (2 information sheets and one action plan). There are no foreseeable risks, side effects, discomforts, inconveniences or restrictions, both immediate and late arising from participation in the study. However, if you become distressed through participation in the surveys, counselling or referral your General Practitioner (with consent) for debriefing may be required and would be arranged by the study investigators.

6. Who should I contact if I have questions?

If you have any questions about the study please contact Dr Alice Bennett, Principal Investigator or A/Prof Jane Andrews. Contact details below.

7. Ethical approval for this study

The study has been given approval by the Royal Adelaide Hospital Human Research Ethics Committee. The research will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research, 2007.

If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the Chairperson, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

Research contact details:

Primary Investigator: Dr Alice Bennett
Gastroenterology Fellow
Level Q7
Department of Gastroenterology and Hepatology
Royal Adelaide Hospital
North Terrace, Adelaide 5000
alice.bennett@health.sa.gov.au
08 8222 4000 0428830979

Co-investigator: A/Prof Jane Andrews
Head of IBD Services
Level Q7
Department of Gastroenterology and Hepatology
Royal Adelaide Hospital
North Terrace, Adelaide 5000
08 8222 4000 or 0417 814 828
Dear Participant,

On behalf of Alice Bennett, a senior Gastroenterology Fellow (specialist in training) at the Royal Adelaide Hospital, and the WCHN Gastroenterology Department, we have contacted you with regards to a research project that she is completing as part of her Inflammatory Bowel Disease Fellowship year in 2013. Her project is being conducted at the Royal Adelaide Hospital and Women’s and Children’s Hospital, under the supervision of myself, Dr David Moore (WCH) and Associate Professor Jane Andrews (RAH) and aims to examine what has happened to patients with childhood onset Inflammatory Bowel Disease (IBD) after going on to adult care. Your name and contact details have not been given to her and remain confidential at the WCH.

You are being contacted because your name and details were on the IBD database as being diagnosed with either Crohn’s Disease or Ulcerative Colitis in childhood and receiving care at the Women’s and Children’s Hospital. This is a research study and you do not have to participate, however, if you do, all information will be treated with absolute confidence.

We believe it is important to find out what has happened to patients with IBD after they leave paediatric care and enter adult medicine, as these are lifelong diseases, and little is known about disease progression and behaviour once people such as yourself, leave paediatric care.

If you choose to participate in the study we ask you to return the enclosed questionnaire and consent form, with questions relating to your health, IBD experience in the transition process and ideas on how the process could be improved. Please refer to the enclosed information sheet for further information regarding the project and questionnaire. If you would prefer to complete the questionnaire by phone or email please indicate this and include your contact details when returning the consent form. The questionnaire will then be sent to you via the preferred avenue or a phone interview will be arranged with you at a convenient time. If you do not wish to participate please return the ‘opt-out’ form. If we do not receive a reply from you, we will send out a reminder letter after 2 weeks and again at 2 months.

Thank you for taking the time to assist with this research project. The data collected may provide vital information regarding the health outcomes of people with paediatric IBD who have transitioned into adult care and highlight possible barriers in the process.

If you require any further information or have questions, please phone the WCH Gastroenterology department (8161 7353) or alternatively the Research offices on the number listed below.

Kind regards,

Dr David Moore
Medical Unit Head
Dept. Gastroenterology
Women’s and Children’s Hospital

On behalf of:

Dr Alice Bennett
Gastroenterology Fellow
Level 17
Royal Adelaide Hospital
North Terrace, Adelaide 5000
alice.bennett@health.sa.gov.au

Assoc. Professor Jane Andrews
Head of IBD Services and Education
Dept. Gastroenterology and Hepatology
Royal Adelaide Hospital
Royal Adelaide Hospital

Dear Participant,

I would like to invite you to participate in a research study being run by Dr Alice Bennett, a senior Gastroenterology Fellow (specialist in training) at the Royal Adelaide Hospital and Flinders Medical Centre. The study is part of her Inflammatory Bowel Disease (IBD) Fellowship year in 2013 and is being conducted at the Royal Adelaide Hospital, Women's and Children's Hospital and Flinders Medical Centre, under the supervision of myself, Associate Professor Jane Andrews (RAH), Associate Professor Peter Bampton and Dr David Moore (WCH). It aims to examine what has happened to patients with childhood onset IBD after going on to adult care. Your name and contact details have been taken from the IBO Service at RAH. This is a research study and you do not have to participate; however, if you do, all information will be treated with absolute confidence.

We believe it is important to find out what has happened to patients with IBD after they leave paediatric care and enter adult medicine, as these are life-long diseases, and little is known about disease progress and behaviour once patients, leave paediatric care. This group of patients has already been surveyed. You are being contacted because you are on the RAH IBO database as being diagnosed with IBD and of a similar age to our surveyed cohort, but were not necessarily diagnosed in paediatric years and consequently did not experience the transition process from paediatric to adult care. Consequently, your opinions regarding the issue of transition care are very important to compare with those who have gone through the transition process.

If you choose to participate in the study, we ask you to return the enclosed questionnaire with questions relating to your health and IBD, and ideas about how the process could be improved. Please refer to the enclosed information sheet for further information regarding the project and questionnaire. If you choose to participate, please return the questionnaire and consent form in the reply paid envelope provided.

If you do not wish to participate, please return the 'opt-out' form. If we do not receive any reply from you, we will send out a reminder letter after 2 weeks and again in 1 month.

Thank you for taking the time to assist with this research project. The data collected may provide vital information regarding the health outcomes of people with paediatric onset IBD who have transitioned into adult care and highlight possible barriers in the process.

If you require any further information or have questions, please phone A/Prof Andrews or phone or email Dr Alice Bennett (details below) or the RAH gastroenterology department 8222 5207.

Kind regards,

Assoc Professor Jane Andrews
Head of IBD Service and Education
Dept Gastroenterology and Hepatology
Royal Adelaide Hospital

Dr David Moore
Medical Unit Head
Dept Gastroenterology
Women’s and Children’s Hospital

Dr Alice Bennett
Gastroenterology Fellow
Level Q7
Department of Gastroenterology
Royal Adelaide Hospital
North Terrace, Adelaide 5000
alice.bennett@health.sa.gov.au
0422 810 973

NB IBD nursing staff can be contacted by email IBDNurse@health.sa.gov.au or by phone 8222 0705

For more appointments at short notice, please consider a personalized referral to the Medicated clinics of Dr Tina, Dr Andrews (Gastroenterology) or Dr LoMos (Hepatology).

Fax all referrals to 9221 5833, attach relevant documentation, and indicate if the patient needs to be booked into a specialist clinic. Contact phone.
Transition Patient Survey: Questionnaire for patients with paediatric onset Inflammatory Bowel Disease that have since transitioned to adult care

Section A – Personal Details

1. Sex
   - Male
   - Female

2. Current Age
   - 18-23
   - 23-28
   - >28

3. Age at diagnosis of IBD

4. Marital status
   - Single
   - In a relationship
   - Married
   - Divorced

5. Postcode
   - As a child:
   - Current:

6. Level of education
   - Primary Completed
     - Year ………………
   - Secondary Completed
     - Year ………………
   - Tertiary Completed
     - Degree………………
   - TAFE Completed
     - Certificate ……………
   - Apprenticeship Completed
     - Type …………………

7. Are you currently employed?
   - Yes
     - If yes:
       - Duration of employment:
       - Part-time/fulltime (please circle)
       - Hours worked per week:
       - Job description:
   - No

Section B – History regarding your Inflammatory Bowel Disease

1. What type of Inflammatory Bowel Disease do you have?
   - Ulcerative Colitis (UC)
   - Crohn’s Disease (CD)
2. If you have UC – do you know how much of your bowel is affected?
   - Yes
   - No
   - If yes, is it:
     - Proctitis (rectum only)
     - Left sided
     - Pancolitis (whole or most of large bowel)

3. If you have Crohn’s – do you know which parts of your gut are affected?
   - Yes
   - No
   - If yes, please specify:

4. Do you have (or have ever had) any perianal disease (fistulas, abscesses in the tissue around the bottom)?
   - Yes
   - No
   - If yes, please specify: (i.e. surgery, abscesses, seton drains etc)

5. What were your main symptoms at the time of your diagnosis of IBD?

6. Do you have (or ever had) any extra-intestinal symptoms (mouth ulcers, eye symptoms, rashes, arthritis etc)? If so, please list

7. Do you have any complications associated with your IBD (bowel perforation, strictures, bowel obstruction etc)? If so, please list

8. Medications
   a. Please list what medications you are currently meant to be taking.
   b. Please also indicate which medications you take regularly and why you might not be taking the others.
   c. Please list the medications that you have taken in the past if they differ from the above.

9. Have you ever had any side effects of any IBD medications? If so, which medication and what happened?

10. How many IBD flares requiring treatment with steroids (prednisolone or intravenous steroids in hospital) have you had:
    a. In the last year? ...........
    b. Since transition into adult care? ...........

11. Have you ever had bowel surgery?
    - Yes
    - No
    - If yes, please answer the following questions
      i. Number of surgeries:
      ii. Age at first surgery:
      iii. Type of surgery
         - Resection with stoma
         - Resection without stoma
12. How many times have you been admitted to hospital because of your IBD?
   a. As a child?
   b. Since leaving paediatric care?

13. Since entering adult care how many different Gastroenterologists have looked after your IBD?

14. Do you currently see a gastroenterologist on a regular basis?
   Yes
   No (if not why not?)
   - If yes, please answer the following:
     a. Are you reviewed in a private practice or at a public hospital (please circle)
     b. If seen in a public hospital, are you seen in a specialised IBD clinic or general Gastroenterology clinic? (please circle)
     c. How often are you reviewed in clinic?
        o Fortnightly
        o Monthly
        o 3 monthly
        o 6 monthly
        o Yearly
        o Other:
     d. If you have a problem between visits what do you do?
     e. Do you feel you know who to contact?
     f. Do you feel adequately supported between visits?

15. If you do not see a gastroenterologist on a regular basis, please answer the following:
   a. Were you referred to a gastroenterologist at the time of transition? Please circle
      i. Yes
         If YES:
            a. Did you see them?
            b. For how long did you see them?
            c. Why did you stop seeing them?
      ii. No
         If NO:
            a. Were you given any info about leaving paediatric care and what to do about IBD once you turned 18?

16. Which of the following members of a multidisciplinary team have you utilised (telephone, email, outpatient appointment) in your adult care?
   o Dietician
   o Nurse practitioner/coordinator
   o Psychologist
   o Specialist bowel surgeon
   o GP

17. What is the main adverse effect of IBD on your life and why?
a. Physical aspect:
b. Social aspect:
c. Psychological aspect:

Section C – Transition from Paediatric to Adult Care – your experience

1. At what age did you transition from paediatric to adult care?

2. Do you know what the plan was for your transition to adult care? Please outline plan.
   - Is that what happened?
     Yes
     No
     If not, why?

3. Do you feel you were part of the decision making?
   Yes
   No
   If not, who was making the decisions?
   And was this with your agreement?

4. To what extent did you feel prepared for the transition?
   - Strongly prepared
   - Slightly prepared
   - Not prepared
   Please comment:

5. Was your care with a public or private gastroenterologist?

6. Have you continued your care with the physician initially referred to at the time of transition?
   Yes
   No
   If not why?

7. Now that you have made the change to adult medicine:
   a. What do you think was done well at the time of your transition?
   b. What do you think was done poorly?

8. Do you feel that the transition process was structured?
   Yes
   No
   Please comment

Section D – Transition from Paediatric to Adult Care – perceived barriers

1. A structured program for the transition of adolescents with IBD to adult care is important for all patients. To what extent do you agree?
   - Strongly agree
   - Agree
   - Neutral
   - Disagree
   - Strongly disagree

2. Which of the following do you think is the most important in determining the timing of transfer of IBD patients from paediatric to adult care?
o Readiness (assessed by career)
o Age 16
o Age 18
o Age 21
o Completion of secondary schooling
o Need for contraceptive/pregnancy advice
o Entering the workforce
o Disease in remission
o High score obtained in a self-efficacy questionnaire completed by the patient
(indicating a knowledge of the disease, diagnostic tests, therapies, medications and complications)

3. If the timing of transition is based on age, at what age do you think the transition process should begin?
   o 15-16
   o 16-17
   o 17-18
   o 18-19
   o 19-20
   o 20-21
   o Depends upon the patient

   Please comment:

4. Do you think that the timing of transition should be different for males and females?
   o Always
   o Sometimes
   o Never
   o Depends on the patient

5. To what extent do you agree with the following statements regarding transition care for adolescents with IBD:
   a. The current transition care program for adolescents is adequate for most patients.
      o Strongly agree
      o Agree
      o Neutral
      o Disagree
      o Strongly disagree
   b. A structured transition program would benefit most patients.
      o Strongly agree
      o Agree
      o Neutral
      o Disagree
      o Strongly disagree

6. What barriers to successful transition from paediatric to adult care do you think exist in adolescent patients with chronic diseases?

7. The following models have been suggested for optimal transition practice in clinic. Which one of the following do you think would be the preferred model to introduce as a part of a structured transition program?
   o The paediatric gastroenterologist should mimic the adult consultation for six months prior to transfer
   o Overlap of paediatric and adult consultations for 6 to 12 months. During this time the patient attends both paediatric and adult hospitals
   o Adult gastroenterologist attends paediatric consultations for 6 months prior to transfer
   o Paediatric gastroenterologist attends adult consultations for 6 months following transfer
o At the time of transfer there is a single clinic appointment attended by the patient, caregiver, nurse coordinator, paediatric and adult gastroenterologist
o Nurse coordinator attends both adult and paediatric consultations with the patient and caregiver over the period of transition (6 to 12 months)
o Nurse coordinator attends first adult consultation with the patient and caregiver at the time of transfer
o Nurse coordinated multi-disciplinary meeting with adult and paediatric gastroenterologists prior to patient transfer to adult care

8. What suggestions would you make if we were designing a new transition process?
Questionnaire for patients with Inflammatory Bowel Disease who have not experienced the ‘transition process’ from paediatric to adult care

Section A – Personal Details

1. Sex
   o Male
   o Female

2. Current Age
   o 18-23
   o 23-28
   o >28

3. Age at diagnosis of IBD

4. Marital status
   o Single
   o In a relationship
   o Married
   o Divorced

5. Postcode
   o As a child:
   o Current:

6. Level of education
   o Primary Completed
     ▪ Year ……………..
   o Secondary Completed
     ▪ Year ……………..
   o Tertiary Completed
     ▪ Degree…………..
   o TAFE Completed
     ▪ Certificate ……………..
   o Apprenticeship Completed
     ▪ Type ………………..

7. Are you currently employed?
   - Yes
     o If yes:
       ▪ Duration of employment:
       ▪ Part-time/fulltime (please circle)
       ▪ Hours worked per week:
       ▪ Job description:
   - No

Section B – History regarding your Inflammatory Bowel Disease

1. What type of Inflammatory Bowel Disease do you have?
   o Ulcerative Colitis (UC)
   o Crohn’s Disease (CD)
2. If you have UC – do you know how much of your bowel is affected?
   - Yes
   - No
     - If yes, is it:
       - Proctitis (rectum only)
       - Left sided
       - Pancolitis (whole or most of large bowel)

3. If you have Crohn’s – do you know which parts of your gut are affected?
   - Yes
   - No
     - If yes, please specify:

4. Do you have (or have ever had) any perianal disease (fistulas, abscesses in the tissue around the bottom)?
   - Yes
   - No
     - If yes, please specify: (i.e. surgery, abscesses, seton drains etc)

5. What were your main symptoms at the time of your diagnosis of IBD?

6. Do you have (or ever had) any extra-intestinal symptoms (mouth ulcers, eye symptoms, rashes, arthritis etc)? If so, please list

7. Do you have any complications associated with your IBD (bowel perforation, strictures, bowel obstruction etc)? If so, please list

8. Medications
   a. Please list what medications you are currently meant to be taking.
   b. Please also indicate which medications you take regularly and why you might not be taking the others.
   c. Please list the medications that you have taken in the past if they differ from the above.

9. Have you ever had any side effects of any IBD medications? If so, which medication and what happened?

10. How many IBD flares requiring treatment with steroids (prednisolone or intravenous steroids in hospital) have you had:
    a. In the last year? ...........
    b. Since transition into adult care? ...........

11. Have you ever had bowel surgery?
    - Yes
    - No
      - If yes, please answer the following questions
        i. Number of surgeries:
        ii. Age at first surgery:
        iii. Type of surgery
          • Resection with stoma
          • Resection without stoma
12. How many times have you been admitted to hospital because of your IBD?
   a. As a child?
   b. Since leaving paediatric care?

13. Since entering adult care how many different Gastroenterologists have looked after your IBD?

14. Do you currently see a gastroenterologist on a regular basis?
   Yes
   No (if not why not?)
   - If yes, please answer the following:
     a. Are you reviewed in a private practice or at a public hospital (please circle)
     b. If seen in a public hospital, are you seen in a specialised IBD clinic or general Gastroenterology clinic? (please circle)
     c. How often are you reviewed in clinic?
        o Fortnightly
        o Monthly
        o 3 monthly
        o 6 monthly
        o Yearly
        o Other:
     d. If you have a problem between visits what do you do?
     e. Do you feel you know who to contact?
     f. Do you feel adequately supported between visits?

15. If you do not see a gastroenterologist on a regular basis, please answer the following:
   a. Were you referred to a gastroenterologist at the time of transition? Please circle
      i. Yes
         If YES:
            a. Did you see them?
            b. For how long did you see them?
            c. Why did you stop seeing them?
      ii. No
         If NO:
            a. Were you given any info about leaving paediatric care and what to do about IBD once you turned 18?

16. Which of the following members of a multidisciplinary team have you utilised (telephone, email, outpatient appointment) in your adult care?
   o Dietician
   o Nurse practitioner/coordinator
   o Psychologist
   o Specialist bowel surgeon
   o GP

17. What is the main adverse effect of IBD on your life and why?
a. Physical aspect:
b. Social aspect:
c. Psychological aspect:

Section C – Transition from Paediatric to Adult Care – perceived barriers

1. A structured program for the transition of adolescents with IBD to adult care is important for all patients. To what extent do you agree?
   o Strongly agree
   o Agree
   o Neutral
   o Disagree
   o Strongly disagree

2. Which of the following do you think is the most important in determining the timing of transfer of IBD patients from paediatric to adult care?
   o Readiness (assessed by career)
   o Age 16
   o Age 18
   o Age 21
   o Completion of secondary schooling
   o Need for contraceptive/pregnancy advice
   o Entering the workforce
   o Disease in remission
   o High score obtained in a self-efficacy questionnaire completed by the patient (indicating a knowledge of the disease, diagnostic tests, therapies, medications and complications)

3. If the timing of transition is based on age, at what age do you think the transition process should begin?
   o 15-16
   o 16-17
   o 17-18
   o 18-19
   o 19-20
   o 20-21
   o Depends upon the patient

   Please comment:

4. Do you think that the timing of transition should be different for males and females?
   o Always
   o Sometimes
   o Never
   o Depends on the patient

5. To what extent do you agree with the following statements regarding transition care for adolescents with IBD:
   a. The current transition care program for adolescents is adequate for most patients.
      o Strongly agree
      o Agree
      o Neutral
      o Disagree
      o Strongly disagree
   b. A structured transition program would benefit most patients.
      o Strongly agree
      o Agree
      o Neutral
6. What barriers to successful transition from paediatric to adult care do you think exist in adolescent patients with chronic diseases?

7. The following models have been suggested for optimal transition practice in clinic. Which one of the following do you think would be the preferred model to introduce as a part of a structured transition program?
   - The paediatric gastroenterologist should mimic the adult consultation for six months prior to transfer
   - Overlap of paediatric and adult consultations for 6 to 12 months. During this time the patient attends both paediatric and adult hospitals
   - Adult gastroenterologist attends paediatric consultations for 6 months prior to transfer
   - Paediatric gastroenterologist attends adult consultations for 6 months following transfer
   - At the time of transfer there is a single clinic appointment attended by the patient, caregiver, nurse coordinator, paediatric and adult gastroenterologist
   - Nurse coordinator attends both adult and paediatric consultations with the patient and caregiver over the period of transition (6 to 12 months)
   - Nurse coordinator attends first adult consultation with the patient and caregiver at the time of transfer
   - Nurse coordinated multi-disciplinary meeting with adult and paediatric gastroenterologists prior to patient transfer to adult care

8. What suggestions would you make if we were designing a new transition process?
Appendix 3: Outpatient IBD Care documents

30 September 2013

Dr Alice Bennett
Gastroenterology
Royal Adelaide Hospital

Dear Dr Bennett,

Re: “Non-specialist outpatient management of ulcerative colitis (UC) – the usefulness and acceptability of three clinical tools.”

RAH PROTOCOL No: 130932.

I am pleased to advise that the Research Ethics Committee has granted approval for the above project on the above date. The following documents have been reviewed and approved:

- Study Protocol Version 1 dated 18 September 2013
- Information Sheet Version 1, dated 18 September 2013
- Questionnaire – Enhancing knowledge regarding the management of Inflammatory Bowel Disease. Survey 1 – IBD guidelines, dated 18 September 2013
- Questionnaire – Enhancing knowledge regarding the management of Inflammatory Bowel Disease. Survey 2 – IBD vs IBS, dated 18 September 2013
- Questionnaire – Enhancing knowledge regarding the management of Inflammatory Bowel Disease. Survey 3 – My Gut (action plan), dated 18 September 2013
- Tool 1 – Clinician’s guide to ulcerative colitis (UC) management, dated 18 September 2013
- Tool 2 – Differentiating IBS and IBD, dated 18 September 2013
- Tool 3 – My Gut Feeling – Patient guide for ulcerative colitis (UC), dated 18 September 2013

Please quote the RAH Protocol Number allocated to your study on all future correspondence. Research Ethics Committee deliberations are guided by the NHMRC National Statement on Ethical Conduct in Human Research 2007.

GENERAL TERMS AND CONDITIONS OF ETHICAL APPROVAL:

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
  (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
  (b) changes to the protocol,
  (c) premature termination of the study,
  (d) a study completion report within 3 months of the project completion.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is ongoing, subject to satisfactory annual review. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each anniversary of the final approval date using the Annual Review Form available at http://www.sah.sa.gov.au/rec/index.jsp. The REC must be advised with a report or in writing when this study is complete so that the file can be closed.

Yours sincerely,

Dr A Thornton
CHAIRMAN
RESEARCH ETHICS COMMITTEE
RESEARCH PROJECT INFORMATION SHEET

Name of study: Primary practitioner outpatient management of Ulcerative Colitis – the usefulness and acceptability of three designed tools.

Principal Investigator: Dr Alice Bennett

Introduction
This is a research study to gather information about the usefulness of three inflammatory bowel disease information tools. Being part of this study may or may not have any benefits for you. You will only be included in this study if you agree to participate.

Details about this study are discussed below. It is important that you take the time to read this document carefully and understand the information in order to decide if you want to participate. This is a research project and you do not have to be involved. You may withdraw from the project at any time after you have commenced.

1. What is the purpose of the study?

We believe it is important to improve the care of patients with Inflammatory Bowel Disease (IBD). One area of care that may potentially be improved is that of out-patient care. Consequently we have designed three separate tools that address this issue. Two of the designed tools are aimed at enhancing General Practitioner knowledge regarding IBD and its management and how it may be differentiated from Irritable Bowel Disease. The final tool is an action plan to be completed by a patient's Gastroenterologist and then used by the patient.

Our study, through the use of three short questionnaires, aims to identify the opinions regarding the content and usefulness of these three tools to see if they would be beneficial to implement in mainstream care in the future.

2. Who is eligible and how many people will be involved in the study?

To be eligible to participate in the study you must be:
• Gastroenterologist or trainee OR
• General Practitioner or trainee

3. What does the study involve?

The study will involve completing 3 short questionnaires relating to the usefulness of three IBD tools. Participation would involve returning the three completed questionnaires in the reply paid envelope provided or completing the questionnaires and handing them back to one of the research staff or to the Shire booth at AGW (for Gastroenterologists and trainees only). Return of a completed questionnaire will be taken as consent.

The questionnaires will take approximately 15 minutes to complete. We ask that you do not include your name on the returned questionnaire.

4. If I take part in this research study, how will my privacy be protected?

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If you consent to participate in the study, we ask that you do not put your name on the questionnaire as the data from the study will remain ‘de-identified’. Information/data from this study may be published in academic journals or discussed at academic meetings, and your personal details will remain confidential.

The data will be stored confidentially, at the Royal Adelaide Hospital at a secure site in locked compacts for 15 years.

5. **Are there any risks if I participate?**

The study involves completion of three short questionnaires relating to the usefulness of three IBD tools (2 information sheets and one action plan). There are no foreseeable risks, side effects, discomforts, inconveniences or restrictions, both immediate and late arising from participation in the study. However, if you become distressed through participation in the surveys, counselling or referral your General Practitioner (with consent) for debriefing may be required and would be arranged by the study investigators.

6. **Who should I contact if I have questions?**

If you have any questions about the study please contact Dr Alice Bennett, Principal Investigator or A/Prof Jane Andrews. Contact details below.

7. **Ethical approval for this study**

The study has been given approval by the Royal Adelaide Hospital Human Research Ethics Committee. The research will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research, 2007.

If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the Chairperson, Research Ethics Committee, Royal Adelaide Hospital on 8222 4139.

**Research contact details:**

**Primary Investigator:** Dr Alice Bennett  
Gastroenterology Fellow  
Level Q7  
Department of Gastroenterology and Hepatology  
Royal Adelaide Hospital  
North Terrace, Adelaide 5000  
alice.bennett@health.sa.gov.au  
08 8222 4000  0428830979

**Co-investigator:** A/Prof Jane Andrews  
Head of IBD Services  
Level Q7  
Department of Gastroenterology and Hepatology  
Royal Adelaide Hospital  
North Terrace, Adelaide 5000  
08 8222 4000 or 0417 814 828
Dear Possible Participant,

I would like to invite you to participate in a research study being run by Dr Alice Bennett, a senior Gastroenterology Fellow (specialist in training) at the Royal Adelaide Hospital. The study is part of her Inflammatory Bowel Disease (IBD) Fellowship year in 2013 and is based out of the Royal Adelaide Hospital and Flinders Medical Centre in South Australia and includes several other tertiary hospitals throughout Australia. It aims to examine your opinions regarding a tool that has been developed to improve the outpatient care of people with ulcerative colitis (UC).

You are being contacted because you are either on the IBD database at one of the participating hospitals as being diagnosed with UC or you may be receiving this invitation via the CGA or IBD Support membership register or website. To participate, you should be over the age of 18 years. This is a research study and you do not have to participate; however, if you do, all information will be treated with confidence. Only de-identified data will be used to help us assess the patient guide.

We believe it is important to improve the management of people with UC. Given that there are few non-gastroenterologistspecialist tools to support this, several tools were developed at a “Clinical Insights” meeting held in early 2013. These tools have been reviewed by Gastroenterologists and General Practitioners (GPs) with some positive feedback. We now wish to obtain the opinions from patients, such as yourself on one specific tool — a patient-held record titled ‘My gut feeling’. The tool is A4 in size and is designed to have some general information, but also to be tailored to your individual situation with the ability to enter personal details about your disease and management. It also allows a tailored plan to be outlined in the case of a flare and would be completed by you and your gastroenterologist.

If you choose to participate in the study we ask that you look at the tool online and complete a short survey on its usefulness, layout etc. If you would prefer to complete the questionnaires by mail please indicate this by replying to this email. We will be sending a reminder email to you in 1 month. If you do not wish to participate you may contact the researchers via email address below to withdraw from the study. Participation in the project is voluntary and a decision not to participate will not affect your current or future treatment.

Thank you for taking the time to assist with this research project. The data collected will be used in conjunction with that received from GPs and Gastroenterologists to improve the tools that will hopefully be used in the near future.

The study has been approved by the RAH research ethics committee who may be contacted on 8222-4135. If you require any further information or have questions, please contact through the RAH gastroenterology department 8222 5207 or Dr Alice Bennett (details below).

Kind regards,

Professor Jane Andrews  
Head of IBD Service and Education  
Dept. Gastroenterology and Hepatology  
Royal Adelaide Hospital

Dr Alice Bennett  
Gastroenterology Fellow  
Level 07  
Department of Gastroenterology  
Royal Adelaide Hospital
Dear Colleague,

As you are aware, Inflammatory Bowel Disease (IBD) is a common, chronic relapsing and remitting condition with an increasing prevalence and consequently, it is a major workload burden for the healthcare system. Whilst patients with acute severe colitis are managed in hospital, patients with mild-moderate disease (and those in clinical remission) are usually managed in the outpatient setting. Despite this, few non-gastroenterologist specialist tools exist that aim to enhance the management of patients with IBD.

This study aims to pilot three IBD clinical tools designed to guide outpatient care of people with UC. The tools have been developed by the 2013 Clinical Insights Steering Committee: A/Prof Jane Andrews (Chair), Ms Stephanie Budkin, Professor Ian Lawrance, A/Prof Rupert Jeong and Dr Gregory Moore. They have been adapted from the outputs of the multidisciplinary Clinical Insights meeting held in Sydney on 10-17 March 2013. Financial support for the meeting and development of these tools was provided by Shire Australia Pty Limited. Cara Lomas of Illior Healthcare Education, Sydney was funded by Shire to provide editorial support to the authors.

The three tools include:

- **IBD guide for non-expert clinicians** — Outlining the way in which the severity and extent of UC are defined and subsequently suggesting management options for GPs based upon these criteria.

- **My gut feeling** — An action plan for patients. Designed to have some generic information, but predominantly to be tailored to the individual patient with allowance to enter specific details regarding their disease and current management. This also allows a specific plan to be outlined in the case of a flare and would be completed by each patient’s gastroenterologist, but to be a patient held record to use with their non-expert clinician.

- **IBD vs IBS** — A guide which outlines key differences in the symptoms and signs of each illness to enable GPs to better differentiate between the two.

As a General Practitioner, you are a key stakeholder and are consequently invited to participate in this study by completing a short questionnaire for each of these 3 tools, aimed at obtaining feedback and acceptability data. We have already assessed the opinions of Gastroenterologists and plan to survey the patients themselves prior to implementing them into mainstream use in a pilot study.

We invite you to view the three tools and then complete three short questionnaires online at the following links:

IBD guide [https://www.surveymonkey.com/s/PP3PQ0](https://www.surveymonkey.com/s/PP3PQ0)
My Gut feeling [https://www.surveymonkey.com/s/FVMYKET](https://www.surveymonkey.com/s/FVMYKET)
IBD vs IBS [https://www.surveymonkey.com/s/PLC5S5F](https://www.surveymonkey.com/s/PLC5S5F)

If you require any further information please do not hesitate to contact me via email.

Thank you for your time.

Kind regards,

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Toolkit survey: Enhancing knowledge regarding the management of Inflammatory Bowel Disease

Survey 1 for GPs and Gastroenterologists– Clinician’s guide to Ulcerative colitis management

1. Do you like the content of the information sheet?
   a. Yes   b. No Please explain

2. Are there any vital pieces of missing information that you feel would be important to include?
   a. Yes   b. No If yes – please describe

3. What do you like BEST about the information sheet?

4. What do you LEAST about the information sheet?

5. Do you like the layout of the information sheet?
   a. Yes   b. No Please explain

6. Do you think that the information sheet would be useful for GPs?
   a. Yes   b. No Please explain

7. Would you have any concerns about GPs using this?
   a. Yes   b. No Please explain

8. Do you think this tool is likely to improve IBD management?
   a. Yes   b. No Please explain
Enhancing knowledge regarding the management of Inflammatory Bowel Disease

Survey 2 for GPs and Gastroenterologists – Differentiating between IBS and IBD

1. Do you like the content of the information sheet?
   a. Yes    b. No    Please explain

2. Are there any vital pieces of missing information that you feel would be important to include?
   a. Yes    b. No    If yes – please describe

3. What do like BEST about the information sheet?

4. What do you LEAST about the information sheet?

5. Do you like the layout of the information sheet?
   a. Yes    b. No    Please explain

6. Do you think that the information sheet would be useful for GPs?

7. Would you have any concerns about GPs using this? Please explain?

8. Do you think this tool is likely to improve IBD management?
   a. Yes    b. No    Please explain
Enhancing knowledge regarding the management of Inflammatory Bowel Disease

Survey 3 for GPs and Gastroenterologists – My gut feeling (action plan)

1. Do you like the content of the action plan?
   a. Yes  b. No  Please explain

2. Are there any vital pieces of information that you feel would be important to include?
   a. Yes  b. No  If yes – please describe

3. What do like BEST about the action plan?

4. What do you LEAST about the action plan?

5. Do you like the layout of the action plan?
   a. Yes  b. No  Please explain

6. Do you think that action plan would be useful for patients?
   a. Yes  b. No  Please explain

7. Do you think that Gastroenterologists will utilise the action plan for their patients?
   a. Yes  b. No  Please explain

8. Do they have safety concerns?
   a. Yes  b. No  Please explain

9. Would you be happy to complete these plans with patients?
   a. Yes  b. No

10. Would you be prepared to endorse them to referring doctors/GP? Patients?
    a. Yes  b. No
Enhancing knowledge regarding the management of Inflammatory Bowel Disease
Survey 1 for UC patients – My gut feeling (action plan)

1. Do you like the content of the patient guide?
   a. Yes  b. No  Please explain

2. Are there any vital pieces of information that you feel would be important to include?
   a. Yes  b. No  If Yes, please describe what information?

3. What do like BEST about the patient guide?

4. What do you like LEAST about the patient guide?

5. Do you like the layout of the action plan?
   a. Yes  b. No  If No, please explain why?

6. Do you think that the action plan would be useful for patients?
   a. Yes  b. No  If No, please explain why?

7. Do you think other patients would use this patient guide?
   a. Yes  b. No  If No, please explain why?

8. Do you have safety concerns with the use of this patient guide?
   a. Yes  b. No  If Yes, please explain these concerns?

9. Would you be happy to use this patient guide?
   a. Yes  b. No  If No, why not?

10. Would you recommend them to other patients with UC?
    a. Yes  b. No  c. Unsure  If No, why not?