

# **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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## *Declaration*

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# *Abstract*

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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 are 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.

# *List of Publications*

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## **Publications resulting from this thesis**

- 1. Bennett AL, Wichmann M, Chin JK, Andrews, JM, Bampton PA.** Rural Inflammatory Bowel Disease care in Australia: disease outcomes and perceived barriers to optimal care. *Health Systems and Policy Research*. 2015; 2 (1:18):1-10.
- 2. Bennett AL, Moore D, Bampton PA, Bryant RV, Andrews JA.** Outcomes and patients' perspectives of transition from paediatric to adult care in Inflammatory Bowel Disease. *World J Gastroenterol*. 2016; 22(8): 2611-2620.  
Doi:10.3748/wjg.v22.i8.2611 PMID: 26937149
- 3. Bennett AL, Munkholm P, Andrews JM.** Tools for primary care management of inflammatory bowel disease: Do they exist? *World J Gastroenterol*. 2015; 21(15): 4457-4465. Doi: 10.3748/wjg.v21.i15.4457 PMID: 25914455
- 4. Bennett AL, Buckton S, Lawrance I, Leong R, Moore G, Andrews JM.** Ulcerative colitis outpatient management: Development and evaluation of tools to support primary care practitioners. *Intern Med J*. 2015; 45(12):1254-66.  
Doi:10.1111/imj.12872 PMID: 26256445

## *Abbreviations*

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<b>5ASA</b>	5-aminosalicylic acid
<b>CD</b>	Crohn's Disease
<b>CCF</b>	Congestive Cardiac Failure
<b>DM</b>	Diabetes Mellitus
<b>ECCO</b>	European Crohn's and Colitis Organisation
<b>FMC</b>	Flinders Medical Centre
<b>GP</b>	General Practitioner
<b>HCP</b>	Healthcare practitioner
<b>IBD</b>	Inflammatory Bowel Disease
<b>RAH</b>	Royal Adelaide Hospital
<b>RRMA</b>	Rural and Remote Metropolitan Areas
<b>SA</b>	South Australia
<b>UC</b>	Ulcerative Colitis
<b>WCH</b>	Women's and Children's Hospital