Crohn's & Colitis Australia

Chronic Inflammatory Condition (CIC) Nurses in Regional Australia

A proposal for Consideration as an Election Commitment

April 2022

Contact: **Leanne Raven**

CEO, Crohn's & Colitis Australia

Contact us here

or call 03 9815 1266

Purpose

The purpose of this document is to outline a proposal to fund a pilot project to appoint 10 multi-specialist registered nurses in regional centres (2 NSW, 2 VIC, 2 QLD and one each for SA, WA, TAS, NT) to trial a novel approach to support people living with chronic inflammatory conditions including:

- rheumatoid arthritis (RA) and other rheumatological conditions (psoriatic arthritis, ankylosing spondylitis, juvenile idiopathic arthritis, giant cell arteritis, ANCA-associated vasculitis and other related inflammatory conditions such as gout)
- inflammatory bowel disease (IBD) (Crohn's disease and ulcerative colitis); and
- psoriasis and other inflammatory dermatological conditions.

The proposal is aimed at addressing the highest priority of the Inflammatory Bowel Disease (IBD) National Action Plan 2019[i] and priority 2.2.3 in the National Strategic Action Plan for Arthritis 2019[ii] which to date are both unaddressed.

The CIC specialist nurse will perform a critical role in regional and rural Australia in line with the National Strategic Framework for Chronic Conditions,[iii] the CIC nurse role supports chronic disease management through:

- Timely and responsive access for the patient to allow early intervention and prevention of disease deterioration and subsequent hospitalisation.
- Additional education and support to improve patient adherence and outcomes.
- Improved safety and monitoring of medications and resulting treatment efficacy.
- A pivotal role in screening that facilitates referral to the multidisciplinary team.
- Relationship to patient which is perceived as more 'equal' than the patient to doctor relationship.[iv,v]

These functions of the role are consistent with the model described in the 2019 Australian College of Nursing (ACN) white paper, *A New Horizon for Health Service: Optimising Advanced Practice Nursing*, in which the specific nursing practice models address fragmented, uncoordinated and expensive care.[vi]

The proposed CICs specialist nurse model is consistent with the prostate cancer specialist nurse role implemented by the Prostate Cancer Foundation of Australia (PCFA).[vii] Nurses' perceptions in this program indicated benefits in service improvement, patient satisfaction, multidisciplinary coordination and disease related information. This model involves embedding nurses in multidisciplinary teams with flexibility to ensure that specialist skills are available to people in rural and remote areas.

About Chronic Inflammatory Conditions

CICs prevalence is increasing throughout the world and particularly in Australia. We expect by 2022 that there will be between 100,000- 160,000 people living with Crohn's disease and ulcerative colitis in Australia[viii,ix]. It is estimated that 1.6 million Australians are living with psoriasis and for Arthritis there are currently 4 million Australians (1.7 million of these have inflammatory arthritis) with projections of 5.4 million Australians by 2030.

These inflammatory conditions are disabling and affect quality of life often resulting in mental health issues such as anxiety and depression. They affect the young disproportionately. All CICs impact health system expenditure significantly and this cost burden will continue to increase in line with prevalence. Estimates for arthritis in the Australian Institute of Health and Welfare 2018/2019 figures for arthritis and MSK were $14 billion, the most expensive disease group in Australia. IBD results in significant costs to society each year: hospital costs for 2012 were estimated to be over $100 million; productivity losses, over $380 million; and total indirect costs over $2.7 billion.

The economic cost estimates are conservative given patients suffering from these conditions have many issues in common and often have co-morbidities across these conditions. Although the manifestations vary according to the organ system involved, they all have symptoms that result from chronic inflammation. These include fatigue, malaise, restriction of activities, and the development of anaemia, a range of irreversible physical disabilities, mental health conditions including anxiety and depressive disorders, and an increased risk of cardiovascular disease and in some of these conditions, premature mortality. People of all ages are affected, often affecting young people in the prime of their lives.

The other feature that these conditions share is the frequent requirement to use similar medications including the "the biologicals". These agents have resulted in a transformation in the quality of life of patients because they suppress chronic inflammation. They are expensive, require close monitoring for potential harms and their use is closely regulated in special programs of the Federal Department of Health Pharmaceutical Benefits Scheme (PBS). The initiation of treatment and ongoing provision of these drugs is restricted to relevant specialists, and requires assessments including the completion of patient diaries, physical examination, and blood test results.

The need

The ongoing management of patients suffering from CICs is best provided by a multidisciplinary team, and nurses have been recognised as the most important component of that team given the complexity and coordination of care required [For example, IBD Standards, Crohn's and Colitis Australia Quality of Care Audit, RA National Action Plan, IBD National Action Plan].

That there are major variations in the availability and access to specialist medical services between metropolitan, regional and rural Australia is beyond question. Sub-optimal care in regional and rural Australia has been demonstrated in many quality studies/ audits and patient experience studies.

The IBD Audit of 71 Australian hospitals, completed in 2016, demonstrated that care is inconsistent across Australia, and that most hospitals fail to meet the Australian IBD Standards for high quality and efficient care:

- Over 5400 admissions per year with an average length of stay of 8 days.
- 60% admitted via the emergency department.
- Only 39% of sites had an IBD nurse.
- 1% of hospitals had a full IBD multidisciplinary team and only half had an IBD helpline (usually staffed by an IBD nurse).[x]

Sites with even a 'Partial IBD Service', which included an IBD nurse, provided significant benefits to patients and savings to the healthcare system such as 15-17% fewer IBD related admissions via Emergency Department.

An Australian study of the IBD patient experience of care in 2018 reinforced the previous IBD Audit results[xi]. From over 1024 respondents this report identifies the needs of people living with IBD:

- 69% have active disease and on average had lived with the condition for 14 years.
- 27% admitted to hospital in last year and 77% of those were unplanned/emergencies.
- Only 32.4% had access to an IBD nurse.

The benefits of specialist CICs nurses are well known, established and documented through research. In addition to reduced emergency department presentations, there is a reduced health system burden due to hospital stays, and outpatient attendances as well as reduced length of stay.[i] Importantly, people living with CICs benefit through improvement in quality of life and health care satisfaction.

Rheumatology nursing care has been shown to be effective in the following areas:

- Patient information, education and self-management support
- Care coordination and continuity of care
- Patient counselling and psychological support
- Supporting disease management including disease monitoring and follow up care, providing rapid access to advice eg during flares (periods when the disease is more active)

Early diagnosis of CICs and referral to specialist care is critical to prevent functional disability, disease progression, social and mental health impacts and healthcare costs.[xii] A recent Australian study found that the median time from symptom onset to initiation of DMARD (biologicals) therapy was around six months, with some patients experiencing delays of up to a year. Reducing delays in initiating DMARD treatment for people with RA has been shown to be cost-effective in the Australian context.[xiii]

Reducing existing delays is also likely to result in substantial cost savings due to lower utilisation of health services, reduced demand for expensive biologic medications, lower levels of disability and improved workforce retention.

Addressing the need

We propose to redress that situation for those suffering from CICs by providing improved treatment options, and ongoing educational and counselling support through a program of specialised nurses in regional centres. These nurses would not be working in isolation but would be part of a multidisciplinary team and would be embedded in existing health services either in General Practice or regional hospitals. They could also be supported by helpline nurses in the patient organisations where they exist and incorporate telehealth services. A major role would be to facilitate and optimise evidence-based access to biological agents by co-ordinating the applications to meet the PBS requirements; educating and supporting patients with their self-injection therapy; coordinating care and education on lifestyle management such as nutrition and physical activity for these group of patients who have increased multi-morbidity. They would also play an educating role for GPs and other health practitioners such as allied health, pharmacists and paramedics in regional and rural locations.

Recognising the need to partner with other stakeholders to make a stronger community impact and create greater efficiencies for the health system in terms of costs, Crohn's & Colitis Australia has obtained the support from the key medical and nursing colleges and patient organisations in rheumatology, gastroenterology, and dermatology. These groups have already collaborated successfully on a major Australian project to optimise health and economic outcomes for biologicals, led by NPS MedicineWise (Value in Prescribing: bDMARDs program). The project produced evidence-based resources optimising their use in Australia and promoting the quality use of medicines. Examples of the resources are available at https://www.nps.org.au/bdmards.

Proposed Structure:

- Project Steering committee with one member from each organisation (see below).
- Lead organisation (CCA) to administer pilot project and develop competencies for the CIC role
- CIC Educational modules – to build on Foundational Course available through the Gastroenterological Nurses College of Australia and online nursing programs at the Australian College of Nursing.
- 10 registered nurses recruited for pilot project

CCA has been working in partnership with all relevant stakeholders to obtain support for the pilot program. In principle support from the following peak medical and nursing organisations and patient groups has been obtained:

- Australian Rheumatology Association (ARA) ,Rheumatology Health Professionals Special Interest Group Association (RHPSIG) and ARA Regional rheumatology Committee
- Gastroenterological Society of Australia (GESA)
- Australasian College of Dermatologists
- Australian College of Nursing
- Gastroenterological Nurses College of Australia (GENCA) and IBD Nurses Association (IBDNA)
- Arthritis Australia
- Crohn's & Colitis Australia
- Psoriasis Australia

Each of these organisations have provided a letter of support.

Funding and costs

We are seeking a federal government contribution of $3.66M over the next three years to pilot the proposal in 7 states and territories and evaluate its effectiveness and impact.

Budget Item	Amount
Employment costs for 10 nurses to be employed for 2 years in regional/ rural locations	~$2,660,000
Accommodation and travel costs for nurses undergoing initial 2-week training in high-volume clinics	$60,000
Development of online foundational education program	$120,000
Fees for 10 nurses to undertake the educational modules	$70,000
Nurse Helpline for 2 years	$170,000
Independent evaluation	$130,000
Project management costs	$450,000
TOTAL for 3 years	**$3,660,000**

About Crohn's & Colitis Australia

CCA is the peak patient organisation that dreams of a future that is free of Crohn's and colitis, empowering people to live fearlessly while we help search for a cure.

CCAs ambition for 2023 is to:

1. Provide omni channel support services with extensive reach and engagement across Australia
2. Be an accessible, fearless and frank communicator and advocate of information and education
3. Measure our organisational impact using data and best available evidence
4. Help in the search for a cure by building research capacity
5. Be recognised as a trusted organisation, respected by others, innovative and financially sustainable

Crohn's & Colitis Australia

For 36 years CCA has worked with our community, government and stakeholders to achieve projects like this proposal by being prudent stewards of funding, effectively partnering to achieve mutual goals including improved quality of care and efficiencies in the health sector, completing projects on time and by promulgating research and findings.

Examples of projects CCA has recently led include:

- Establishment of the first consensus Australian IBD Standards,
- First national IBD Audit involving 71 hospitals
- The largest Australian IBD patient experience of care research survey, and
- Development of the Australian Government's IBD National Action Plan
- Consumer Awareness and Education Project funded by DOH (in progress)
- GP and Physician IBD Education Project funded by DOH (in progress)
- National Paediatric Hospital IBD Audit funded by DOH (in progress)

References

[i] Commonwealth of Australia (Department of Health). Inflammatory Bowel Disease National Action Plan Inflammatory. March 2019 available at https://www.crohnsandcolitis.com.au/ibdqoc/ibd-national-action-plan/

[ii] Commonwealth of Australia (Department of Health). National Strategic Action Plan for Arthritis 2019. Available at: https://www.health.gov.au/sites/default/files/documents/2020/08/national-strategic-action-plan-for-arthritis_0.pdf

[iii] Australian Health Ministers' Advisory Council, "National Strategic Framework for Chronic Conditions," (2017), Australian Government, Canberra.

[iv] O'Connor M, Bager P, Duncan J, Gaarenstrom J, Younge L, Detre P, et al. N-ECCO consensus statements on the European nursing roles in caring for patients with Crohn's disease or ulcerative colitis. J Crohns Colitis 2013;7(9):744–64. Available from: https://doi.org/10.1016/j.crohns.2013.06.004

[v] Inflammatory Bowel Disease Clinical Update 2018, Gastroeneterological Society of Australia. Available at: http://www.gesa.org.au/ resources/clinical-guidelines-and-updates/inflammatory-bowel-disease/

[vi] Australian College of Nursing (ACN). 2019, 'A New Horizon for Health Services: Optimising Advanced Practice Nursing—A White Paper by ACN 2019', ACN, Canberra.

[vii] Sykes J, Yates P and Langbecker D. Evaluation of the implementation of the prostate cancer specialist nurse role. Cancer Forum, Vol. 39, No. 3, Nov 2015: 199-203. Available at: https://search.informit.com.au/documentSummary;dn=791979940308603;res=IELHEA> ISSN: 0311-306X.

[viii] PricewaterhouseCoopers Australia (PwC). Improving inflammatory bowel disease care across Australia. March 2013. Available from: https://www.crohnsandcolitis.com.au/research/studies-reports

[ix] Businge D, Pollack A, Chidwick K (2021) Prevalence of inflammatory bowel disease in the Australian general practice population: A cross-sectional study. PLoS ONE 16(5): e0252458. https://doi.org/10.1371/journal.pone.0252458

[x] Crohn's & Colitis Australia. Inflammatory Bowel Disease Audit. 2016. Available from: https://www.crohnsandcolitis.com.au/ research/ studies-reports/

[xi] Mikocka-Walus A et al. Quality of Care in Inflammatory Bowel Disease: Actual Health Service Experiences Fall Short of the Standards. Internal Medicine Journal 09 November 2019 https://doi.org/10.1111/imj.14683

[xii] Van Eijk-Hustings Y, van Tuberg A, Bostrum C et al 2011. EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis. Ann Rheum Dis 2011 doi:10.1136/annrheumdis-2011-200185

[xiii] Van Doornum S, Tropea J, Tacey M, Liew D. 2013. Time to Institution of disease modifying anti-rheumatic drugs in Australian patients with early RA. American College of Rheumatology Annual Meeting (Poster)

Crohn's & Colitis Australia

For information please contact:
Leanne Raven
CEO, Crohn's & Colitis Australia

T 03 9815 1266
Contact us here
W crohnsandcolitis.org.au
P PO Box 777, Camberwell South. VIC 3124

Copyright 2022 © Crohn's & Colitis Australia