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20 December 2019

The Hon. Greg Hunt, MP
Minister for Health
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

Dear Minister Hunt

Re: 2020-21 Pre-budget submission - Inflammatory Bowel Disease (IBD) Nurses and Education

Crohn's & Colitis Australia (CCA) is pleased to present this submission for the implementation of specialist IBD nurse roles and education that will build national capacity in the health system to improve the health care of 85,000 Australians living with IBD.

Since the launch of the IBD National Action Plan in March 2019, CCA has been working with IBD Nurses Australia (IBDNA), philanthropic organisations, hospitals and members of CCA to address the highest priority of the **IBD National Action Plan**. This unfunded priority continues to have wide stakeholder and patient support because of the evidence-based impact it will have on the quality of care for people living with Crohn's disease and ulcerative colitis.

An investment by the Australian Government in support of this proposal in the **2020 World Health Organisation (WHO) Year of the Nurse** will make a real difference by contributing funds for the establishment of a model that will endure beyond the 3-years and provide the following benefits:

- Reduction in the community burden through efficient health care;
- Improvements in quality of care for people living with Crohn's disease and ulcerative colitis; and,
- Increased leverage for CCAs to secure philanthropic and state/territory government funding to ensure ongoing sustainability of this model.



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The timing of this Australian Government investment would not only align with WHO Year of the Nurse theme but will occur whilst we are experiencing an increase in prevalence of IBD with an estimated 100,000 people expected to be living with IBD in Australia by 2022.

We invite the Australian Government to partner with CCA, IBDNA, philanthropy, stakeholders and consumers to co-create a model of care and education for those who are missing out on important, effective chronic disease management.

I look forward to hearing from you about the proposal and would be delighted to discuss the request in more detail at your convenience.

IBD is a young person's disease that people live with for life. Your support in WHO Year of the Nurse can make a life-changing difference for young people who lack access to vital services and strengthen the Australian community.

Yours sincerely

A handwritten signature in black ink that reads 'A.K. Raven'.

Associate Professor Leanne Raven RN
Chief Executive Officer

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Inflammatory Bowel Disease (IBD) Nurses and Education - Pre-budget submission

Crohn's & Colitis Australia

Inflammatory Bowel Disease (IBD) Nurses and Education

A proposal for
2020-21 Pre-Budget Submissions

20 December 2019

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Purpose

The purpose of this document is to outline a proposal to increase access to specialist IBD nurses to support people living with IBD and to develop and deliver IBD specific education for nurses. The proposal is aimed at addressing the highest priority of the Inflammatory Bowel Disease (IBD) National Action Plan.ⁱ

About IBD

IBD prevalence is increasing throughout the world and particularly in Australia. Crohn's disease and ulcerative colitis, the most common forms of IBD, are chronic, disabling, life-limiting gut conditions that disproportionately affect the young and can result in frequent hospitalisation and surgeries for the 85,000 Australians living with IBD. In addition to the extensive physical symptoms the impact on mental health and societal participation are often limiting. 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. We expect by 2022 that there will be 100,000 people living with IBD in Australia.ⁱⁱ

The need

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).ⁱⁱⁱ

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 reinforces the previous IBD Audit results.^{iv} 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 IBD 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 IBD benefit through improvement in quality of life and health care satisfaction.

Addressing the need

Specialist IBD nurses

As described in the IBD National Action Plan "Specialist IBD nurses perform a critical role in the high provision of high quality IBD care". In line with the National Strategic Framework for Chronic Conditions,^v the IBD 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.^{vi, vii}

These functions of the role are consistent with the model described in the recently released 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.^{viii}

The proposed specialist IBD nurse model is consistent with the prostate cancer specialist nurse role implemented by the Prostate Cancer Foundation of Australia (PCFA). Nurses' perceptions in this program indicated benefits in service improvement, patient satisfaction, multidisciplinary coordination and disease related information.^{ix} This model involves embedding a specialist nurse in a multidisciplinary team in hospital/community. The model also incorporates the flexibility to ensure that specialist skills are available to people in rural and remote areas.

The CCA specialist IBD nurse model will:

- Implement a “hub and spoke” model of nurses providing specialist services and incorporating outreach to rural and remote areas;
- Embed nurses in hospital teams with funding coordinated via CCA and agreements with hospitals in the states and territories to address sustainability;
- Collaborate with Health Care Homes, general practices and other primary care facilities to ensure seamless patient-centred care;
- Provide linkages with existing IBD nurse helplines; and
- Incorporate telemedicine clinics.

The model will see the establishment of 15 specialist IBD nurse positions over three years. The roles would be incrementally expanded over three years from 5 to 15 and will seek to build capacity delivering specialised IBD nursing services to areas of need, particularly remote and regional areas. The implementation of the roles will support state/territory and local health services to realise the benefit of specialist IBD nurse roles and build business cases for the continuation of effective roles beyond the 3-year funded project. Appropriate evaluation to examine the impact on hospital demand, quality of care and cost benefit will be undertaken.

Education

Complementing the nurse positions will be a program to develop and deliver IBD specific education for nurses. The Gastroenterological Nurses College of Australia special interest group, Inflammatory Bowel Disease Nurses Australia (IBDNA), have developed and delivered effective elements of IBD nurse education and have been exploring opportunities with CCA to expand the training modules into a program of introductory, foundation and advanced schools resulting in a recognised graduate diploma. This project will implement this plan to ensure that specialist IBD nurses have the education required to support the practice pathways outlined by the ACN which have been confirmed in the recent review of nurse education; *Educating the Nurse of the Future* conducted by Emeritus Professor Steven Schwartz AM.^x

Funding and costs

CCA has been building relationships with philanthropy over the last six months to investigate feasible ways to fund the highest priority of the *IBD National Action Plan*. **CCA is seeking a Government contribution of \$2.3 million dollars over the next three years** to be matched by CCA funds raised through philanthropy and state/territory governments to achieve a funding total of \$4.6 million dollars, outlined below.

Priority Area	Action	Cost
1. A skilled and accessible multidisciplinary workforce		
1.1 Increased access to specialist IBD nurses	a) Implement specialist IBD nurse positions to address demand and increase access in areas of need	\$4.11M over 3 years
	b) Develop specialist IBD nurse training modules	\$449K over 3 years
Total		\$4.559 M over 3 years

About Crohn's & Colitis Australia

CCA is the peak consumer not-for-profit organisation for 85,000 people living with IBD in Australia. Our Vision is to empower people to live life at full potential as we search for a cause and cure for Crohn's and colitis. Our purpose is:

- System change and improvement in quality of care,
- Engage with, empower and educate people living with Crohn's and colitis, health care professionals and carers,
- Raise awareness of Crohn's and colitis and promote gut health within the community, and,
- Build research capacity in the search for a cause and cure for Crohn's and colitis.

For 34 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, completing projects on time and by promulgating research and findings.

Examples of projects CCA has recently lead include:

- establishment of the first consensus Australian IBD Standards,
- first national IBD Audit
- the largest Australian patient experience of care research survey, and
- drafting of the Australian Government's IBD National Action Plan.

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

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

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

^{iv} 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>

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

^{vi} 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>

^{vii} Inflammatory Bowel Disease Clinical Update 2018, Gastroenterological Society of Australia. Available at: <http://www.gesa.org.au/resources/clinical-guidelines-and-updates/inflammatory-bowel-disease/>

^{viii} Australian College of Nursing (ACN). 2019, 'A New Horizon for Health Services: Optimising Advanced Practice Nursing—A White Paper by ACN 2019', ACN, Canberra.

^{ix} 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.

^x Schwartz, S. Commonwealth of Australia (Department of Health). Educating the Nurse of the Future – Report of the Independent Review into Nursing Education. December 2019, available at:

<https://www.health.gov.au/resources/publications/educating-the-nurse-of-the-future>