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Re: Official Information Act request – Inflammatory Bowel Disease Nurse

I refer to your Official Information Act request received dated 21 September 2021 requesting the following information:

- 1. A copy of the business plan to hire a paediatric Inflammatory Bowel Disease Nurse at Starship, and the date it was submitted and to whom.**
- 2. Any and all information available regarding the decision or action taken on the business plan (such as committee minutes) referenced in item 1.**
- 3. A list of all new positions at Auckland DHB that have been approved for funding in the previous twelve months and their salaries. If salary information is confidential, please just provide a list of newly funded positions.**

Response

- 1. A copy of the business plan to hire a paediatric Inflammatory Bowel Disease Nurse at Starship, and the date it was submitted and to whom.**
- 2. Any and all information available regarding the decision or action taken on the business plan (such as committee minutes) referenced in item 1.**

Please find attached an informal proposal that describes a paediatric inflammatory bowel disease pilot at Starship Child Health. This proposal includes an Inflammatory Bowel Disease (IBD) Nurse Specialist role. The proposal was shared with Starship Foundation in February 2019 to explore funding opportunities. There are no formal minutes regarding decisions taken and the Starship Foundation continue to pursue funding opportunities as they arise. Unfortunately, there is no certainty with regards to timeframes for securing funding.

In the meantime, Starship is continuing to implement service improvements that are components of this programme as funding and capacity in the current COVID-environment allows. As described in previous correspondence, this includes pathway development including a database (in progress), IBD email address as a central point of contact, the introduction of an IBD clinic and transitional clinics with adult services (all completed).

3. **A list of all new positions at Auckland DHB that have been approved for funding in the previous twelve months and their salaries. If salary information is confidential, please just provide a list of newly funded positions**

Auckland DHB increased its Full Time Equivalent staffing by 321 in the period between September 2020 and September 2021. Much of the overall increase can be attributed to COVID related roles (360 FTE were employed in COVID-related roles during period). Another significant change was additional roles relating to safe staffing (Care Capacity and Demand Management) calculations which are part of a national programme to balance DHBs' capacity to care (staff skills, numbers and mix, beds and equipment – with patient demand).

	FTE Change
Total FTE - Actual	(September 2020 to September 2021)
Medical	20
Nursing	117
Allied Health	51
Support (e.g. Laundry and Cleaners)	-3
Administration	136
Total	321

You are entitled to seek a review of the response by the Ombudsman under section 28(3) of the Official Information Act. Information about how to make a complaint is at www.ombudsman.parliament.nz or freephone 0800 802 602.

Please note that this response, or an edited version of this response, may be published on the Auckland DHB website.

Yours sincerely,



Ailsa Claire, OBE
Chief Executive

Proposal Inflammatory Bowel Disease Pilot Starship Child Health

BACKGROUND

What is IBD?

- Inflammatory bowel disease (IBD) encompasses a number of chronic relapsing gastrointestinal diseases, predominantly Crohn's disease and ulcerative colitis
- The precise cause of IBD remains unknown but there are a number of known genetic predispositions with poorly identified environmental triggers
- A number of children have significant co-existent medical conditions, notably liver disease, eye involvement and arthritis
- While IBD can present at any age, around a quarter of cases present in childhood, especially during the pre-pubertal and pubertal years
- Internationally, IBD incidence in childhood has increased throughout the 2000s and continues to do so

Why is it important to provide early effective treatment to children with IBD?

- Symptoms of IBD are initially non-specific meaning that there is usually a lag phase of months to years between the onset of symptoms and diagnosis
- This means that childhood IBD often impacts upon growth, development and puberty and involves more extensive portions of the bowel than in adult patients
- Treatment of IBD is complex but excellent, validated protocols exist and are supported by international experts and professional societies representing IBD clinicians and patients
- Children should be treated differently to adults due to the long-term impact of some medications (especially steroids) on growth and bone health
- A significant proportion of children with IBD will require surgery which can be complex and should be carefully considered given the potential need for repeated surgery
- Effective treatment results in clinical remission of disease with good long-term outcomes
- The goal of treatment is to achieve clinical remission as soon as possible in the disease course to minimise both long-term morbidity related to the disease and to the side effects of the drugs used
- Treatment should be multidisciplinary addressing the nutritional and psychosocial impact of the disease as well as the medical and surgical effects
- Management of IBD by multidisciplinary teams has been shown to improve outcomes and has become the standard of care of children with IBD in most major equivalent centres worldwide eg UK, US, Canada and Australia

Inflammatory bowel disease in New Zealand children

- New Zealand has one of the highest rates of childhood IBD in the world (Lopez et al, 2018)
- Cases of very early onset IBD (VEO-IBD) in infants have increased in recent years. These cases often have a genetic basis and are often more medically complex
- Approximately 30 new cases of IBD are diagnosed annually at Starship Child Health, including children from all around the North Island. This represents an increase from 20 cases per year 5-10 years ago
- At any time, approximately 150 patients are in active follow-up by Starship Child Health
- For reasons which we do not understand, we have observed clusters of disease out of keeping with population size eg in Bay of Plenty and Hawkes Bay
- A larger proportion of patients than expected have significant liver disease with a number having undergone liver transplantation
- We observe a high rate of psychosocial morbidity as a result of IBD, often related to chronic pain, stigma of gastrointestinal symptoms, school absenteeism and so on

What do we do well in managing paediatric IBD at Starship Child Health?

- A survey carried out by us in 2018 of IBD patients from the Auckland region identified our staff as highly rated by patients.
- We have short clinic and endoscopy waiting times and are able to provide investigation and diagnosis of IBD quickly after referral
- Our senior medical and dietetic staff contribute to the National Child and Youth Network for Paediatric Gastroenterology and a national protocol for managing paediatric IBD in the New Zealand context is available
- We provide high quality nutritional treatment of Crohn's disease and have high rates of patient commencing treatment
- Our senior medical staff are able to keep up to date with international developments in the diagnosis and management of IBD via networking with an extensive network of colleagues overseas and opportunities for Continued Professional Development
- Patients outside Auckland are managed via an extensive network of Paediatric Gastroenterology outreach clinics, in conjunction with shared care relationships with local General Paediatricians

What do we do less well in managing paediatric IBD at Starship Child Health?

- Education for newly diagnosed cases is provided on an ad hoc basis by Paediatric Gastroenterologists
- There is no particular focus of IBD expertise or interest within General Paediatricians outside Starship
- Care provided to children outside Auckland between outreach clinics is highly variable despite national protocols eg initial investigation may be undertaken in adult gastroenterology and surgical input may be provided by adult or paediatric surgery
- There is no dedicated FTE for psychology input to these patients
- There is no Nurse Specialist resource for case co-ordination and patient education
- Families of IBD patients experience frustration in not having an obvious point of contact for concerns between clinic appointments regarding disease flares, medication side effects and psychosocial concerns. This leads to patients self-presenting to the Children's Emergency Department or their local hospital with higher rates of admission than expected.
- We observe higher than expected rates of patients refusing conventional medical or surgical therapy for IBD and seeking alternative therapies without any evidence base
- We are currently out of step with equivalent overseas centres that manage children under a dedicated IBD service
- We not collect rigorous prospective data such as surgery complication rates and progression to biologic therapy, which would enable quality benchmarking with equivalent paediatric IBD services
- We rarely contribute to collaborative research on IBD in children and yet we care for a unique group of patients in whom we have made important observations regarding disease phenotype and progression
- There is little interaction with the main community support service ie Crohns and Colitis NZ

BUSINESS CASE TO DEVELOP A FORMAL SERVICE FOR CHILDREN WITH IBD

What is being proposed?

Piloting of a formal service for children with inflammatory bowel disease, including

- A multidisciplinary IBD service with medical, dietetic, nursing, surgical and psychological input
- A dedicated IBD clinic with provision for patients to be seen at short notice when they have disease flares
- Enhanced education and provision of patient resources from the time of diagnosis
- Creation of a consistent point of contact for patients and families between appointments, especially those experiencing disease flares
- Seamless interaction with related services especially paediatric surgery and adult gastroenterology

- Creation of a prospectively managed IBD database to allow reporting of key outcome data eg progression to biologic therapy or surgery and to allow benchmarking with other equivalent paediatric IBD services
- Improved integration of hospital- and community-based care with involvement of Crohns and Colitis NZ

What is required?

- Nurse Specialist in IBD at 0.5 FTE to provide
 - Initial disease education
 - Ongoing disease education for adolescents before and during transition to adult services
 - Liaison between adult and paediatric services for patients in transition to adult services
 - Point of contact for patients and families between clinic appointments when there are concerns about treatment plans or disease flares
 - Provide liaison between Starship Child Health services and local DHB services by development of professional networks and contacts
 - Case coordination for patients living outside Auckland
- Psychologist to support the IBD service 0.5 FTE
 - Initial evaluation of disease effects and quality of life to allow early intervention
 - Ongoing evaluation in patients with non-adherence, school absenteeism and disengagement from follow-up
 - Support to patients undergoing transition from paediatric to adult services
 - Liaison with education services for patients experiencing school absenteeism
- Upskilling of both nurse and psychologist via a period of observership at an equivalent paediatric IBD centre eg Royal Children's Hospital, Brisbane
- Development of patient educational resources
- Database development to allow capture of prospectively collected data and key performance indicators, further allowing benchmarking with other centres
- The above FTE would be for a fixed term of 3 years as a pilot programme in order to build an informed business case for an ongoing service

What is the return on investment?

- Reduced hospital admissions and Emergency Department presentations
- Increased clinic activity with patients being seen more often in clinics rather than being admitted
- Better capture of virtual work and non-patient contact work
- Improved patient engagement and satisfaction as measured by
 - Clinic attendance rates
 - Lower rates of progression to non-validated complementary therapies
 - Repeat patient satisfaction survey
- Improved patient outcomes – there are data to show that the sooner patients achieve disease remission, the longer this will last
- Some returns such as improved long-term outcomes, reduction of surgical rates and reduced use of biologic therapies may be realised in adult services

How does this meet standard practice?

- We do not conform with standard international practice of caring for children with IBD in not offering a dedicated clinic nor Nurse Specialist input
- In the New Zealand Society of Gastroenterology 2018 publication A Critical Analysis of the Gastroenterology Specialist Workforce in New Zealand; Challenges and Solutions prepared for the Ministry of Health, it is noted that there are 18 Nurse Specialists working with adult patients with IBD in New Zealand and yet none for paediatric patients

- We have sought advice from equivalent Australian and UK centres all of whom run a multi-disciplinary paediatric IBD service
- We have specific links to Royal Children's Hospital (Brisbane), Hospital for Sick Children (Toronto) and Royal Hospital for Children (Glasgow). The population base for Brisbane and Glasgow in particular are very similar to New Zealand, providing excellent opportunities for collaboration and benchmarking

What are the implications for clinician time?

- Medical staff FTE does not need to be increased as medical staff will be relieved of some of the paramedical and administrative work they are currently providing
- Dietetic FTE can remain the same at present as the dietitians' time can be better organised by the cohorting of IBD patients into a dedicated clinic and by nurses providing education and a point of contact rather than the dietitians providing this

Estimated set up costs

- Nurse Specialist 0.5 FTE \$50,000 pa x 3 years = \$150,000
- Psychologist 0.5 FTE \$40,000 pa x 3 years = \$120,000
- Development of educational resources approximately (one-off) = \$20,000
- Database development approximately (one-off) = \$20,000
- Administrator to enter existing patient's data 0.2 FTE for 3 months (one off) = \$5,000
- The Nurse Specialist and Psychology FTE is requested for a fixed term of 3 years as a pilot in order to build an informed business case for an ongoing service
- **TOTAL** = approximately \$300,000 - \$350,000 over 3 years

What facilities and consumables are required?

- Existing gastroenterology clinics would be re-configured to create an IBD clinic
- New staff would require desk spaces and access to IT and telephone services

What are the consequences of not doing this?

- There is a risk of us our practice becoming further removed from standard international best practice with associated poorer patient outcomes compared to international comparator groups

Anything else you think is relevant to making this business case

- We have already commenced an IBD improvement project within Paediatric Gastroenterology in order to better inform a longer-term strategic plan for managing paediatric IBD
- We are seeking to partner with Crohn's and Colitis NZ with particular reference to support worker input and creation of patient resources which could be used nationwide
- We have the benefit of being able to communicate with shared care consultants and other interested clinicians via the National Child and Youth Network for Paediatric Gastroenterology
- We have approached the Paediatric Gastroenterology service at Lady Cilento Hospital, Brisbane which has a similar patient population to us in an effort to provide mentorship with the set-up of a new IBD service and a mechanism for benchmarking patient outcomes

Helen Evans
Service Clinical Director