

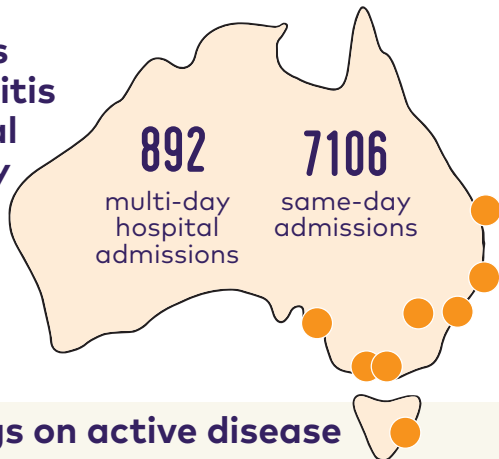
# Paediatric Crohn's and Colitis

## Hospital Audit and Patient Experience Australia



### Crohn's and colitis hospital activity 2021

Source AIHW



### CCA hospital audit and patient experience

**8** hospitals audited  
**23%** of national public overnight admissions audited 2021

**266** teens and parents surveyed  
**35** family interviews

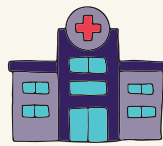
### Findings on active disease



**49%**  
Anaemia



**37%**  
Malnutrition



**47%**  
Hospitalised twice in 2 years



**45%**  
Emergency admission

### Limited multidisciplinary care



Only **23%** of CD in-patients were seen by an IBD nurse



**28%** cases with psychological comorbidity  
**0** psychologists on the team at any site

Down from 2014, when one site included a psychologist

### Clinical gaps in hospitals

**30%** 2014  
**10%** 2021

Lower use of preventive anti-thrombotic

Despite new clinical guidelines that reinforce its use



**56** young people using new, off-label IBD medications

Off-label - compassionate dosing or paying

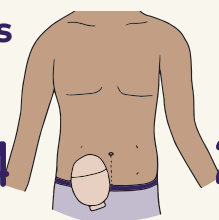
### Improving outcomes

IBD-related surgery has not increased from 2014 to 2021

CD remains steady

**16%** 2014  
**5%** 2021

UC surgical admissions



Reduced use of corticosteroids for 3+ months in the year prior to admission

**10%** 2014  
**1%** 2021

Corticosteroids have harmful cumulative side effects



### Recommendations



Improve mental health support



Increase support for the multidisciplinary team



Streamline access to newer medications



Improve pre-diagnosis experience



Scan to view the full reports

[crohnsandcolitis.org.au](http://crohnsandcolitis.org.au) 1800 138 029

[crohnsandcolitis.org.au/advocacy/our-projects/ibd-paediatric-quality-of-care](http://crohnsandcolitis.org.au/advocacy/our-projects/ibd-paediatric-quality-of-care)

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# What they said

## Stories of patient experience

"I found it frustrating when we first started on board. Um, no one picked up on this, which was fine, I understand, but we got told, 'Wait, wait, let's see what happens.' And, you know, the weight was dropping off her and you could clearly see something was wrong, to the point where it got urgent and months later it was sort of too late, and then hospitalisation and feeding tube and all that kind of stuff."

Mother of a 14-yo living with Crohn's disease

"He cried a lot in toilet and he was just feeling... Like he loved to play soccer and at one stage he was not feeling like he's gonna play soccer at all one day. He was thinking he like his life is almost gone and it's, it's, really like heartbreaking for parents for mum and dad both."

Mother of a 9-yo living with ulcerative colitis

"They've all been like offered to me [multidisciplinary specialists]... but once we are home and in the [local] region, there's really nothing"

Mother of a regionally located 16-yo living with Crohn's disease

"Um, so that, that's my big thing. That these kids need to be having help in, in the, the minefield of the emotions and the predictions and the thoughts and the worries. You know, that come with all this physical stuff and all the multitude of needles and scans and surgeries and pain and, you know, that, that isn't really addressed by the doctors because that's not what they're there to do."

Mother of a 17-yo living with Crohn's disease

"I don't know if there are any dietitians that specialise in IBD, but to have had that opportunity initially would have been brilliant. Um, and we trust our consultant [...] he's been very trustworthy and very good information, but there hasn't been much focus on it. Just really like, 'no, eat whatever, you'll be fine.' and then let's move on to the next conversation."

Mother of a 6-yo with Crohn's disease

"He actually went into a simulated machine, an MRI machine, before he had the actual real one. [Interviewer: Yes] So, that he had an understanding. He's sort of always been the kid that's, um, he likes to know. Knowledge is power for [youth]. Um, and, you know, they were there holding his hand all, you know, on the day of the procedures, but now he's, they've helped him so much that [youth] can tackle these things all by himself."

Mother of a 15-yo living with Crohn's disease