## Assessing Patient-Perceived Burden Of Disease In Crohn's Disease: A Novel Scoring Approach In A Real-World Australasian Cohort

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### INTRODUCTION & AIM

- The prevalence and burden of inflammatory bowel diseases (IBD), including Crohn's disease (CD), are rising.
- Crohn's Colitis Care (CCCare) is a cloud-based IBD-specific electronic medical record (EMR) used at IBD centres across Australia and New Zealand (NZ) since 2018.
- Aim: to describe the patient-perceived burden of disease (PPBoD) in people with CD using a novel score in a large realworld Australasian cohort.

#### METHODS

- Data from CCCare flow across to a de-identified clinical quality registry, which was interrogated in Oct 2023.
- A novel PPBoD score was designed for CD. It included multiple patient-reported outcomes including some from validated indices (such as the Harvey-Bradshaw index).
- A total score of 0 was defined as no PPBoD, 1-2 mild, 3-4 moderate and  $\geq$  5 significant PPBoD.
- Correlations amongst PPBoD and demographics, disease and treatment factors were explored.

| A measure of sleep<br>disturbanceA measure of<br>confidence & anxiety<br>around incontinenceA symptom<br>recognised to alarm<br>consumersA measure of the<br>quanta of interruption<br>to daily activitiesA global<br>asses0 = None<br>$1 = \ge 1 \text{ nocturnal}$<br>bowel motion0 = No urgency<br>$1 = Hurry$<br>$2 = Immediately3 = Incontinence0 = None1 = Mild2 = Moderate3 = Severe0 = None1 = Severe0 = Less thanusual or same asusual2 = 3 \text{ to } 4movements morethan normal3 = 5 \text{ or more}movements more0 = Ve4 = T$   |
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| $\begin{array}{c c} 0 = \text{None} \\ 1 = \geq 1 \text{ nocturnal} \\ \text{bowel motion} \end{array} \begin{array}{c c} 0 = \text{No urgency} \\ 1 = \text{Hurry} \\ 2 = \text{Immediately} \\ 3 = \text{Incontinence} \end{array} \begin{array}{c c} 0 = \text{None} \\ 1 = \text{Mild} \\ 2 = \text{Moderate} \\ 3 = \text{Severe} \end{array} \begin{array}{c c} 0 = \text{None} \\ 1 = 1 \text{ to } 2 \\ \text{movements more} \\ 1 = \text{Slight} \\ 2 = 3 \text{ to } 4 \\ \text{movements more} \\ 1 = 3 \text{ to } 4 \\ 3 = 5 \text{ or more} \end{array} \begin{array}{c c} 0 = \text{None} \\ 1 = 1 \text{ to } 2 \\ \text{movements more} \\ 1 = \text{Slight} \\ 2 = 3 \text{ to } 4 \\ \text{movements more} \\ 3 = 5 \text{ or more} \end{array} \begin{array}{c c} 0 = \text{None} \\ 1 = \text{Slight} \\ 2 = 1 \\ 3 = 5 \text{ or more} \end{array} \end{array}$ |
| than normal  |

### RESULTS

- 3,461 people with CD were included, 3,233 (93.4%) of whom had adequate data to calculate PPBoD.
- o 74.7% Australian (n=2,414); 25.3% NZ (n=819).
- Gender varied significantly between PPBoD categories, whereas age and BMI did not.

|   | None<br>(n = 1,418)      | Mild<br>(n = 1,163)   | Moderate<br>(n = 426) | Significant<br>(n = 226) | p value |
|---|--------------------------|-----------------------|-----------------------|--------------------------|---------|
| Median age, years<br>(IQR)  | 40.0<br>(30.0 –<br>54.0) | 41.0 (30.0<br>- 56.0) | 44.0 (33.0 –<br>56.0) | 42.5 (32.0 –<br>55.0)    | 0.45    |
| Female, n (%)   | 600 (42.3)               | 590 (50.7)            | 253 (59.4)            | 138 (61.1)               | < 0.001 |
| Median BMI, Kg/m²<br>(IQR)  |                          | 25.6 (22.4<br>- 29.4) | 25.4 (22.3 –<br>29.4) | 25.7 (22.8 –<br>30.2)    | 0.003   |
| Country of Origin<br>Australia, n (%)                               | 1092<br>(77.0)           | 873 (75.1)            | 302 (70.9)            | 147 (65.0)               | 0.0003  |
| Advanced therapy, n<br>(%)  | 801 (56.5)               | 689 (59.2)            | 241 (56.6)            | 101 (44.7)               | 0.01    |
| Steroids, n (%)   | 18 (1.3)                 | 19 (1.6)              | 15 (3.5)              | 11 (4.9)                 | < 0.001 |
| Aminosalicylates, n<br>(%)  | 216 (15.2)               | 143 (12.3)            | 58 (13.6)             | 33 (14.6)                | 0.16    |
| Immunomodulator, n<br>(%)   | 548 (38.7)               | 453 (39.0)            | 158 (37.1)            | 89 (39.4)                | 0.52    |
| One or more days out<br>of role due to CD, n<br>(%)                 | 13 (1.1)                 | 56 (6.3)              | 35 (6.0)              | 43 (28.1)                | < 0.001 |
| Faecal calprotectin<br><100 ug/g, n (%)                             | 256 (58.1)               | 226 (57.1)            | 71 (45.8)             | 38 (46.3)                | 0.01    |
| Complete<br>endoscopic <u>and</u><br>radiologic remission,<br>n (%) | 247 (55.9)               | 168 (46.9)            | 64 (42.1)             | 38 (39.2)                | < 0.001 |





### RESULTS (CONT.)

- 80.0% had no or mild PPBoD. People with lower PPBoD: o were more likely to be receiving advanced therapies
- o had lower rates of steroid use.
- No significant differences in immunomodulator and/or aminosalicylate use was seen across PPBoD categories.
- Significantly higher PPBoD was seen in NZ. Notably, people in NZ were less likely to be receiving advanced therapies (p < 0.001).
- 1,074 (33.2%) had a recent faecal calprotectin (FCP) result.
- o Those with no PPBoD were more likely to have biochemical remission  $(FCP < 100 \mu g/g).$
- data recorded.
- o Those with no PPBoD were more likely to be in remission.
- Those with higher PPBoD had more days out of role due to CD recorded. Less than 1% of those with no PPBoD had days out of role recorded.

#### CONCLUSIONS

- Within this geographically dispersed cohort, the majority had either no or mild PPBoD, which correlated with objective measures of remission.
- People with increasing PPBoD had greater time out of role and were less likely to be in faecal calprotectin, endoscopic or radiologic remission. There appear to be opportunities with up titrating therapy to address this issue.
- Advanced therapy use appeared to be protective against high PPBoD, and their broader health economic value could be evaluated using this tool.

# CROHN'S COLITIS

#### • Only 1,049 people (32.4%) had endoscopic and radiological remission