

CCCure received project funding from The Helmsley Charitable Trust to undertake this analysis.

BACKGROUND

- Around 10% of people with inflammatory bowel diseases (IBD) are diagnosed in childhood.
- Crohn's Colitis Care is a cloud-based IBD-specific electronic medical record (EMR) used at IBD centres across Australasia since 2018. Paediatric functionality was built into CCCare to support whole of life care documentation.
- Aim: report on real-world characteristics of children with IBD using data entered into CCCare during routine practice.

METHODS

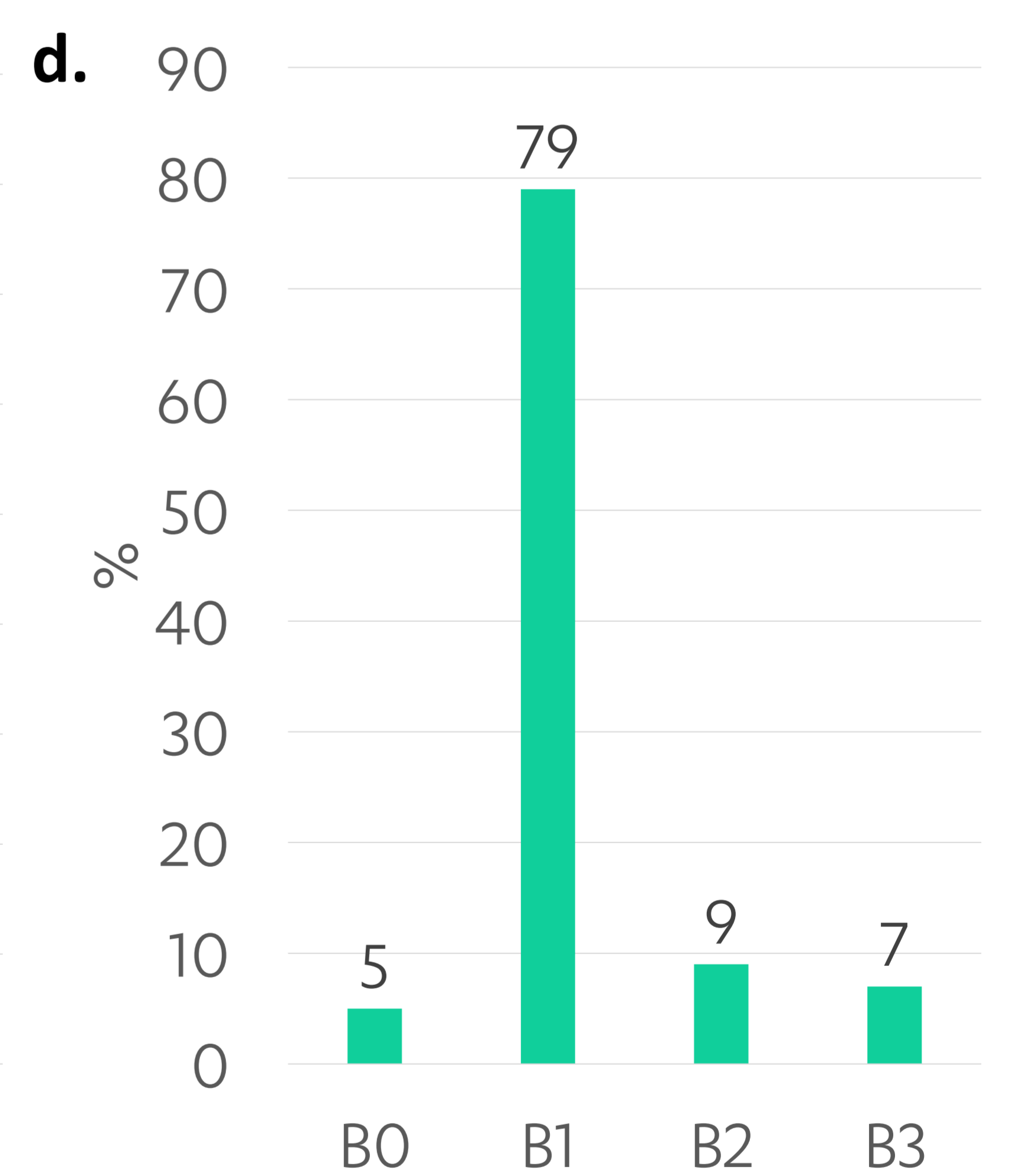
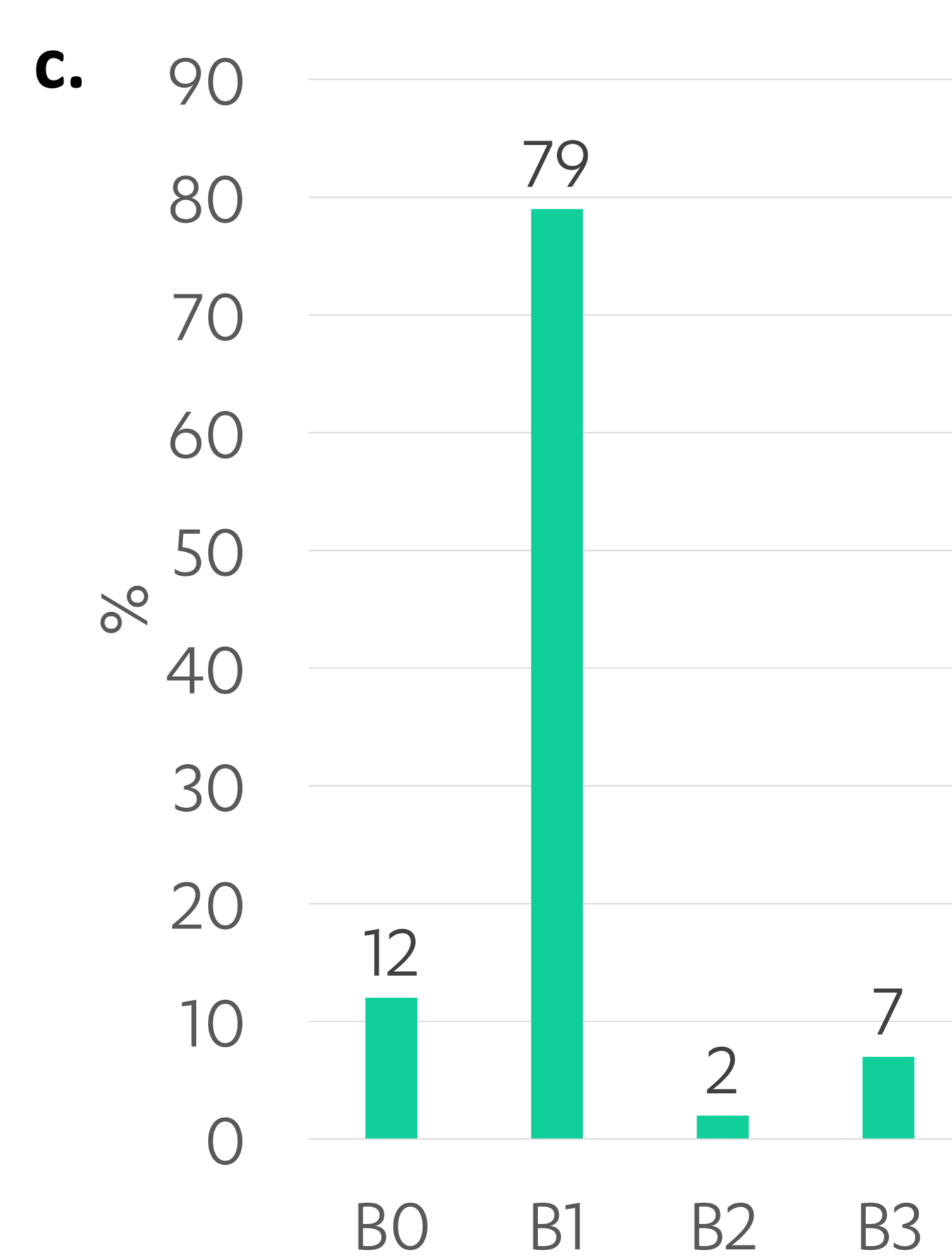
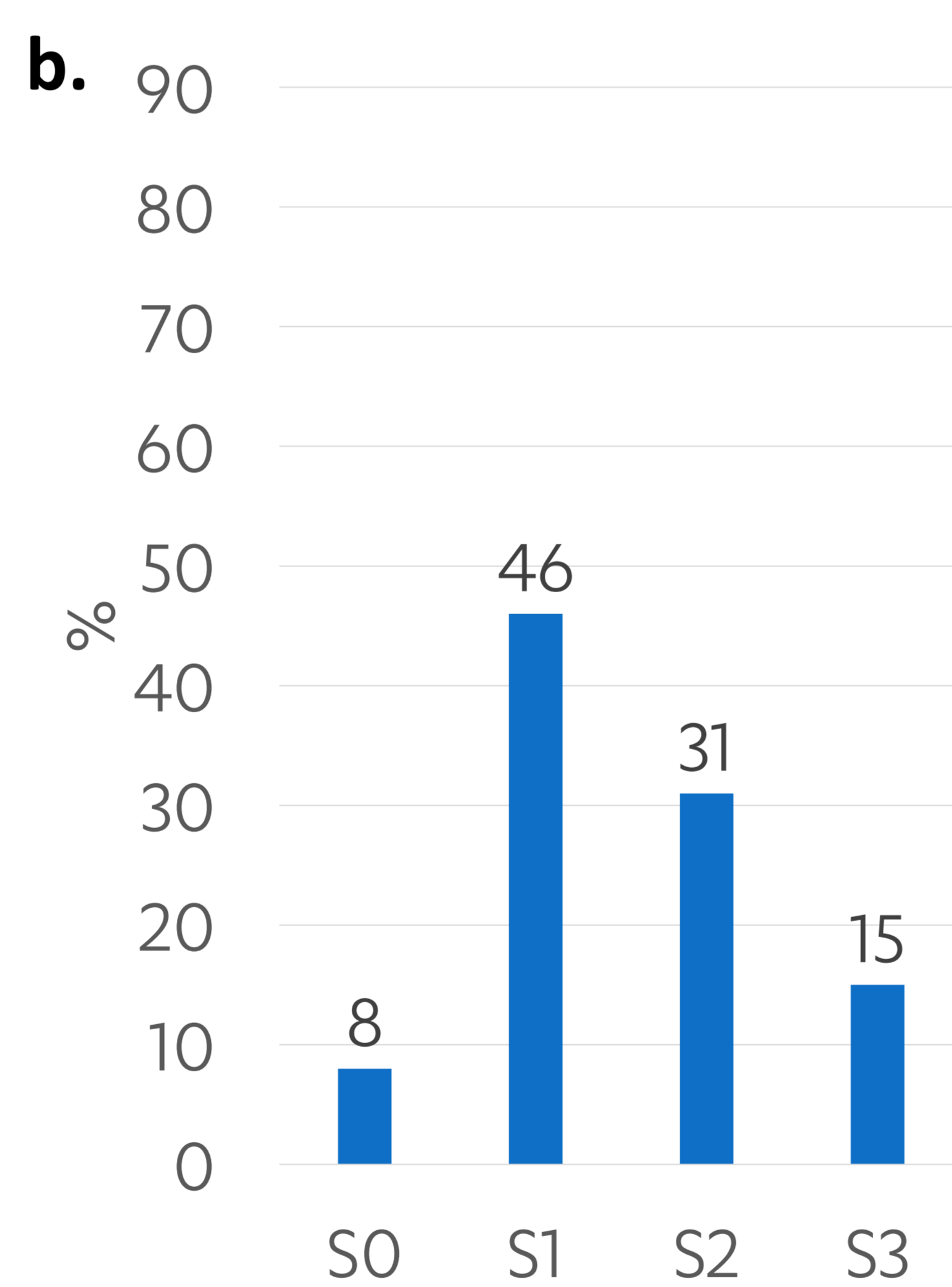
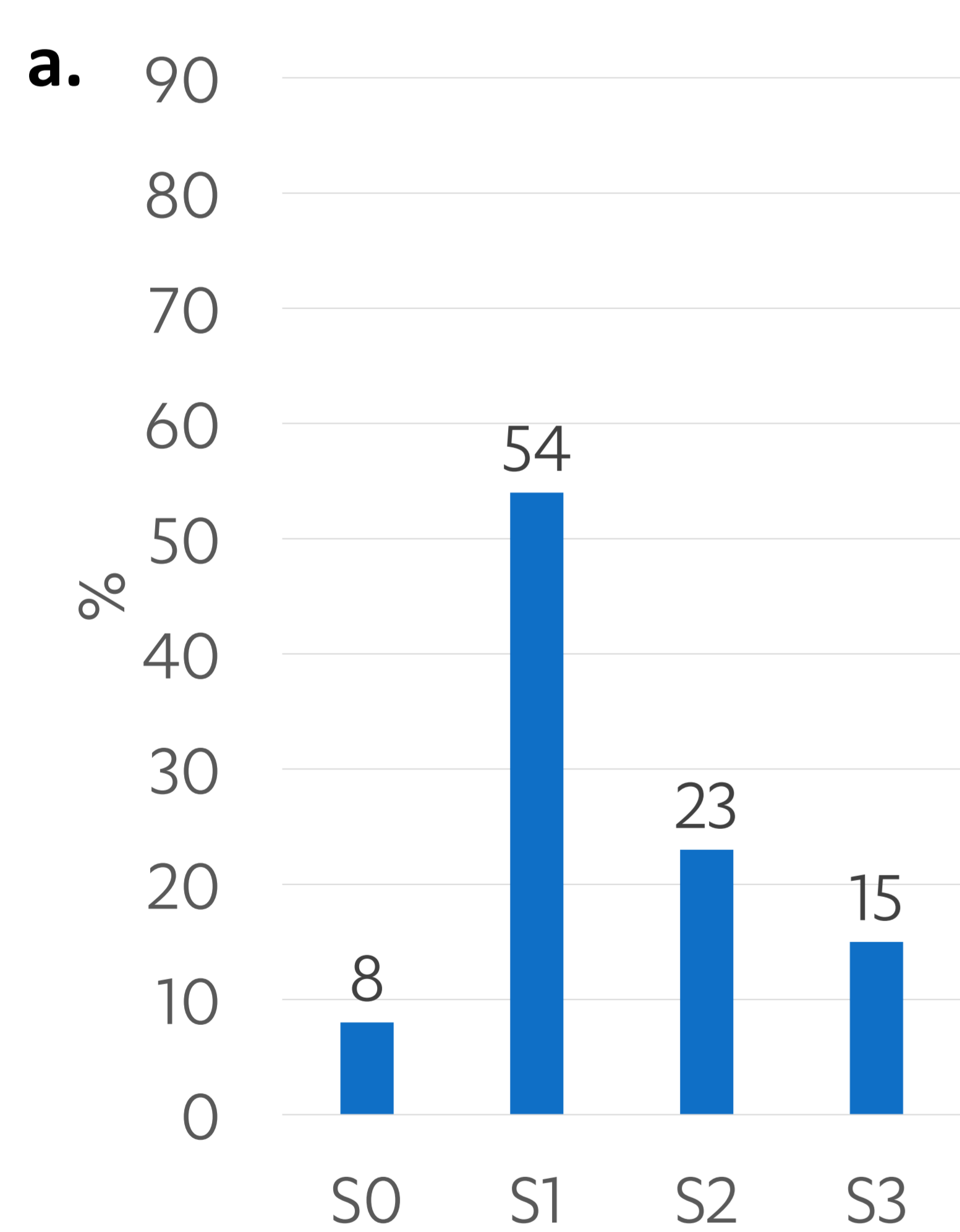
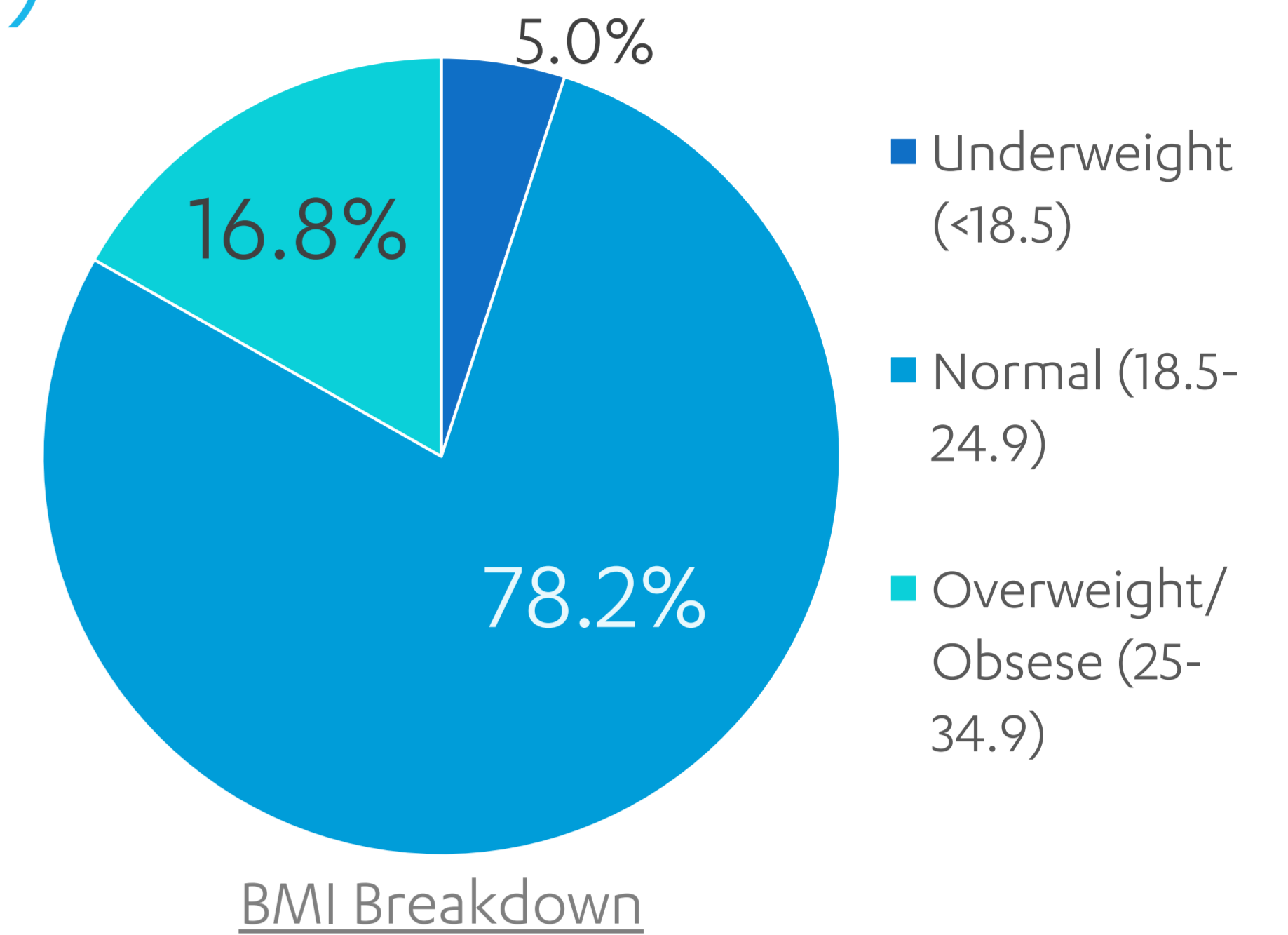
- Data from CCCare flow across to a de-identified clinical quality registry, which was interrogated in Nov 2023.
- Clinical data for all children (<18 years at date of extract) under active care (encounter within 14 months) were included.

RESULTS

- 162 children across 14 centres were analysed.
- Gender split roughly equal (male=55.0%), with a minority aged <10 years (9.9%, n=16).
- 64.8% (n=105) had Crohn's disease (CD), 31.5% (n=51) ulcerative colitis (UC) and 3.7% (n=6) IBD-unclassified.

RESULTS (CONT.)

- Mean recorded body mass index (BMI) was 20.5kg/m² (n=101)
- 7.4% (n=12) were currently receiving steroids, and 55.6% (n=90) had received an advanced therapy (biologic or small molecule).
- Few reported incontinence (3.1%, n=5), and 6% (n=9) had an IBD-related surgery recorded.
- ~20% (11/56) had current or previous fistulising CD.
- On most recent data, the mean faecal calprotectin (FCP) was 637µg/g
- On most recent data, mean overall C-reactive protein was 5.26mg/L (n=42) (CD = 6.03mg/L; UC= 3.55mg/L)
- On most recent data, mean overall ESR was 7.15mm/hr (CD = 5.63mm/hr; UC= 12.28mm/hr)
- Disease severity was higher in people with UC (S2 & S3) compared to people with CD (B2 & B3) (below).



Disease Activity as recorded in Phenotype. a. Most Recent Phenotype (UC), b. Cumulative Phenotype (UC), c. Most Recent Phenotype CD, d. Cumulative Phenotype (CD). Abbreviations: S0, remission at present; S1, mild disease; S2, moderate activity; S3, severe disease; B0, no visible inflammation; B1, inflammatory disease only; B2, stricturing +/- inflammation; B3, Penetrating intra-abdominal disease (abscess/perforation/phlegmon).

CONCLUSIONS

These prospectively collected data from large Australasian IBD treatment centres show:

- Despite high use of biologics and normal serum markers, patients had relatively high FCP results, suggestive of active disease.
- The overall cohort currently had mild disease severity (based on phenotype). Disease severity was greater in people with UC based on severity ratings and ESR results.
- CCCare collates data at scale across a large geography. Data can be re-analysed longitudinally to identify changes over time and better define differences between paediatric and adult-onset IBD.

