

# Hydration knowledge, attitudes and practices among people living with an ileostomy: A cross-sectional multinational survey

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## Research Article

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# Abstract

## Purpose

Individuals living with an ileostomy (ileostomates) are at risk of dehydration owing to fluid and electrolyte losses through stoma output, particularly those with a high output stoma (HOS). Yet, there is limited evidence on hydration-related knowledge, attitudes and practices among ileostomates. This study investigated indicators of dehydration among ileostomates in the UK, Ireland and Australia, exploring how they related to knowledge of hydration and associated barriers and behaviours.

## Methods

A cross-sectional online survey was completed by ileostomates ( $n = 366$ ). Measures included indicators of hydration status, fluid and dietary intake behaviours, hydration knowledge, perceived barriers (*i.e.*, convenience, knowledge, monitoring) and self-management strategies. Participants were classified as having normal or HOS based on estimated output relative to fluid intake.

## Results

One third of participants were classified as having HOS, and 48% were dehydrated according to self-reported urine colour. HOS was associated with greater medication burden, higher dehydration symptom score, shorter time since surgery, female sex, and residence in Australia. Hydration knowledge was low and did not differ by output category. Greater barriers to hydration were associated with increased dehydration symptoms and lower fluid intake, fruit and vegetable intake, and hydration knowledge.

## Conclusion

Dehydration and HOS are persistently challenging for ileostomates. Suboptimal hydration knowledge, inconsistent translation of clinical guidance into practice, modifiable behavioural and clinical factors contribute to dehydration risk, highlighting the need for proactive, targeted hydration education and ongoing monitoring beyond the postoperative period.

## Introduction

Hydration is fundamental to human health; even mild dehydration has been associated with impaired physiological functioning, while more severe dehydration is associated with increased morbidity [1, 2] and healthcare utilisation [3]. Effective hydration regulation relies on coordinated behavioural, renal and gastrointestinal (GI) mechanisms, with the colon playing a key role in fluid and electrolyte homeostasis [4].

Ileostomy is a common surgical procedure in the treatment of GI diseases [5], whereby the ileum is surgically exited through the abdominal wall; digestive material bypasses the colon and is diverted into a disposable pouch [6]. Current figures estimate some 67 500 people across the UK and Ireland, and a further 18 000 in Australia are currently living with an ileostomy [7–9]. Individuals living with an ileostomy (ileostomates) lack the absorptive capacity of the colon and are at an increased risk of dehydration owing to substantial losses of fluid and

electrolytes through stoma output [10, 11]. High output stoma (HOS), typically defined as output exceeding 1–2 L/day [12–15], further increases dehydration risk. However, the clinical significance of stoma output depends on the balance between output and oral intake [16], with a recent consensus panel recommending that HOS classification should not be defined solely on output volume and should integrate multiple clinical factors to form a broader assessment, including postoperative physiology, pharmacological influences, nutrition and fluid intake behaviours [17].

HOS affects approximately 15–30% of ileostomates postoperatively, and is associated with renal impairment, malnutrition and peristomal skin complications [18–20]. Yet, hydration management and HOS prevention are poorly understood [21, 22], resulting in variation in clinical practice and diminished patient understanding [23]. These challenges are likely influenced by differences in healthcare systems and access to specialist support and follow-up care [24]. Existing research has focused predominantly on clinical outcomes and postoperative complications, with limited attention given to patient knowledge, perceived barriers to maintaining hydration and behavioural practices. For instance, ileostomates are often advised to limit fruit and vegetable (FV) consumption to reduce stoma output [10, 25], while increasing salt intake to compensate for intestinal sodium losses [10, 16], both of which may influence hydration status. Addressing this gap is essential for developing effective solutions to improve hydration status and associated outcomes in this population. Therefore, this study aimed to determine ileostomates' hydration-related behaviours and knowledge, and to identify factors that contribute to dehydration and HOS across the UK, Ireland and Australia.

## Methods

### Study design

A cross-sectional online survey was conducted to assess indicators of dehydration and hydration-related behaviours among ileostomates. Anonymous responses were collected from participants in the UK, Ireland and Australia between December 2024 – May 2025 following ethical approval from Ulster University (FCBMS-24-170-A) and reciprocal approval by Victoria University.

### Participant sampling

Due to the exploratory nature of the study, there was no formal power calculation. Based on a previous stoma-related lifestyle study [26], a minimum target of 240 responses was set. Participants were recruited via website and social media platforms of relevant support organisations (e.g., Ileostomy Association, Crohn's and Colitis Australia). Participants accessed the study information via a web-link included within recruitment materials and could then decide whether to give their consent and complete the survey.

### Survey instrument

The survey was designed and presented in REDCap (v.14.5.32) and integrated previously validated questionnaires [27–30] alongside feedback from a UK patient and public involvement group, to ensure suitability for use in an ileostomate population. Country-specific versions of the questionnaire were distributed to account for minor linguistic and cultural differences between Australian and UK/Irish populations. Adaptations were restricted to terminology (e.g., “peppers” vs “capsicum”) and did not alter questionnaire content, scoring or constructs

measures. Consequently, questionnaire validity and reliability were considered unchanged. Data collected included demographics, indicators of hydration status, hydration-related intake behaviours, knowledge and perceived barriers. An optional section explored self-management practices using closed and open-ended questions. Survey scales and scoring are summarised in Table 1.

## Indicators of hydration

Participants reported stoma pouch type (*i.e.*, manufacturer, size, product name or code where available), frequency of emptying, and a percentage estimation of pouch fullness upon emptying. These data were used to estimate daily ileostomy output; participants were classified as having HOS if estimated output exceeded estimated fluid intake [16]. Output consistency was assessed using a validated output consistency scale [31]. Urinary output was assessed using self-reported frequency and volume measures across multiple timepoints and converted to a composite urinary output score. Severity of dehydration was assessed using a urine colour chart [30] and a survey specific dehydration symptom scale comprising 9 common symptoms (*e.g.*, thirst, lack of concentration, fatigue) [32–35]. Participants indicated the frequency of each symptom on a 5-point scale and responses were summed to generate an overall symptom score, with higher scores indicating greater dehydration symptom burden.

## Intake behaviours

FV intake, salt usage (*i.e.*, adding during cooking or to meals) and fluid intake were assessed using the EPIC-Norfolk Food Frequency Questionnaire [28] and a 17-item beverage frequency questionnaire [29]. Habitual daily intake was estimated using established scoring procedures [36].

## Hydration knowledge and perceived barriers

Validated hydration knowledge and barrier scales were adapted for use within an ileostomate population [27]. The knowledge scale assessed understanding of hydration-related concepts, with higher scores indicating greater knowledge of hydration. The barriers scale examined factors relating to convenience (*i.e.*, access to fluids and toilet facilities), knowledge (*i.e.*, understanding of hydration with an ileostomy), and monitoring (*i.e.*, tracking fluid intake and output), with higher scores indicating more severe barriers to hydration.

Table 1  
Survey scales and scoring information

| Scale                                                 | Number of items | Categorical ordinal response |                       | Assigned numerical value | Maximum possible score |
|-------------------------------------------------------|-----------------|------------------------------|-----------------------|--------------------------|------------------------|
| Urinary output <sup>a,b</sup>                         | 8               | Output frequency             | Never                 | 0                        | 96                     |
|                                                       |                 |                              | Rarely                | 1                        |                        |
|                                                       |                 |                              | Sometimes             | 2                        |                        |
|                                                       |                 |                              | Usually               | 3                        |                        |
|                                                       |                 |                              | Always                | 4                        |                        |
|                                                       |                 | Output volume                | A small amount        | 1                        |                        |
|                                                       |                 |                              | A medium amount       | 2                        |                        |
|                                                       |                 |                              | A large amount        | 3                        |                        |
| Dehydration symptoms <sup>a</sup>                     | 9               |                              | Never                 | 0                        | 36                     |
|                                                       |                 |                              | Rarely                | 1                        |                        |
|                                                       |                 |                              | Sometimes             | 2                        |                        |
|                                                       |                 |                              | Usually               | 3                        |                        |
|                                                       |                 |                              | Always                | 4                        |                        |
| Hydration knowledge <sup>c</sup> [27]                 | 15              |                              | Definitely inaccurate | -2                       | 30                     |
|                                                       |                 |                              |                       | -1                       |                        |
|                                                       |                 |                              | Probably inaccurate   | 0                        |                        |
|                                                       |                 |                              | Not sure              | 1                        |                        |
|                                                       |                 |                              | Probably accurate     | 2                        |                        |
| Hydration Facilitators and barriers <sup>d</sup> [27] | 11              |                              | Definitely accurate   |                          | 55                     |
|                                                       |                 |                              | Not at all like me    | 1                        |                        |
|                                                       |                 |                              |                       | 2                        |                        |
|                                                       |                 |                              | Not much like me      | 3                        |                        |
|                                                       |                 |                              | Somewhat like me      | 4                        |                        |
|                                                       |                 |                              |                       | 5                        |                        |
|                                                       |                 |                              | Mostly like me        |                          |                        |
|                                                       |                 |                              | Very much like me     |                          |                        |

<sup>a</sup> Study specific scale.

<sup>b</sup> Assigned numerical value for output frequency multiplied by assigned numerical value for output volume.

<sup>c</sup> Scoring presented for true statements; false statements reverse scored.

<sup>d</sup> Scoring presented for statements relating to barriers; facilitators to hydration reverse scored.

## Data analyses

Statistical analyses were conducted using SPSS (IBM SPSS Statistics v.30). Shapiro-Wilk test was used to test normality of all data. Continuous data are presented as mean  $\pm$  SD if normally distributed and median (interquartile range [IQR]) for non-parametric distributions. Categorical variables are presented as percentage of group count. Differences between UK/Irish and Australian populations were assessed using independent samples *t*-test and Mann-Whitney U test for parametric and non-parametric data respectively. Pearson's Chi-square test was used to compare proportions of categorical variables between groups. The same analysis was repeated comparing differences between participants classified as experiencing a normal versus high output. Bivariate correlation analyses were conducted to explore relationships between hydration knowledge, barriers to hydration and selected indicators of hydration and intake behaviours. One-way ANOVA or Kruskal-Wallis tests were conducted to compare outcomes according to time since ileostomy surgery (0–2 years, 3–7 years and > 7 years).

Summative content analysis was used to analyse open-ended text responses [37]. Individual codes were organised into main categories and subcategories and are presented as the total frequency (*n*, %) which each code appeared in the responses.

## Results

### Sample description

The survey was accessed by 527 respondents and completed by *n* = 366 (69.4% completion rate) predominantly from UK and Ireland (*n* = 291, 79.5%). Participants were grouped according to output category and differences between groups are summarised in Table 2. A greater proportion of female (81.1% vs 71.7%, *p* = 0.014) and Australian (27.0% vs 17.2%, *p* = 0.028) participants were classified as having a high output. Additionally, time since ileostomy surgery was significantly lower (3.1 [1.0, 7.9 vs 4.3 [1.5, 11.6] years; *p* = 0.033) and the number of medications taken was significantly greater in the high output group (3.0 [1.0, 5.0] vs 2.0 [1.0, 4.0]; *p* = 0.030). Other demographic and clinical variables were comparable between groups.

Table 2  
Descriptive characteristics for participants with normal or high output stoma.

| Characteristics (Median [IQR])        |                    | All (n = 366)     | Normal output (n = 244) | High output (n = 122) | P-Value           |
|---------------------------------------|--------------------|-------------------|-------------------------|-----------------------|-------------------|
| <b>Demographics</b>                   |                    |                   |                         |                       |                   |
| Age (years)                           |                    | 52.0 (41.0, 62.0) | 53.0 (41.0, 63.0)       | 50.5 (42.8, 61.0)     | 0.544             |
| Sex (%)                               | Male               | 24                | 27.9                    | 16.4                  | <b>0.014</b>      |
|                                       | Female             | 74.9              | 71.7                    | 81.1                  |                   |
|                                       | Other              | 0.1               | 0.4                     | 2.5                   |                   |
| BMI (kg/m <sup>2</sup> )              |                    | 26.6 (23.0, 31.6) | 26.7 (23.3, 31.6)       | 26.6 (22.1, 31.2)     | 0.594             |
| Location (%)                          | UK/ Ireland        | 79.5              | 82.8                    | 73.0                  | <b>0.028</b>      |
|                                       | Australia          | 20.5              | 17.2                    | 27.0                  |                   |
| Number of medications                 |                    | 2.0 (1.0, 4.0)    | 2.0 (1.0, 4.0)          | 3.0 (1.0, 5.0)        | <b>0.030</b>      |
| Reason for ileostomy (%)              | Ulcerative Colitis | 36.6              | 36.9                    | 36.1                  | 0.591             |
|                                       | Crohn's disease    | 21.9              | 23.4                    | 18.9                  |                   |
|                                       | Cancer treatment   | 19.1              | 19.7                    | 18.0                  |                   |
|                                       | Diverticulitis     | 3                 | 2.5                     | 4.1                   |                   |
|                                       | Other              | 19.4              | 17.6                    | 23                    |                   |
| Time since ileostomy (years)          |                    | 3.8 (1.4, 10.1)   | 4.3 (1.5, 11.6)         | 3.1 (1.0, 7.9)        | <b>0.033</b>      |
| <b>Indicators of dehydration</b>      |                    |                   |                         |                       |                   |
| Output consistency (%)                | Normal             | 50.8              | 55.6                    | 41.3                  | <b>0.011</b>      |
|                                       | Loose or watery    | 49.2              | 44.4                    | 58.7                  |                   |
| Urine colour (%)                      | Euhydration        | 51.6              | 52.0                    | 50.8                  | 0.824             |
|                                       | Dehydration        | 48.4              | 48.0                    | 49.2                  |                   |
| Urinary output scale                  |                    | 44.0 (33.0, 55.0) | 44.0 (34.0, 54.8)       | 44.0 (32.0, 56.0)     | 0.963             |
| Dehydration symptom scale (Mean ± SD) |                    | 17.0 ± 6.0        | 16.3 ± 5.7              | 18.5 ± 6.5            | <b>&lt; 0.001</b> |
| Ileostomy output (L/day)              |                    | 1.5 (1.1, 2.0)    | 1.3 (1.0, 1.7)          | 2.1 (1.6, 2.9)        | <b>&lt; 0.001</b> |

| Characteristics (Median [IQR])           | All (n = 366)    | Normal output (n = 244) | High output (n = 122) | P-Value           |
|------------------------------------------|------------------|-------------------------|-----------------------|-------------------|
| <b>Demographics</b>                      |                  |                         |                       |                   |
| <b>Intake behaviours</b>                 |                  |                         |                       |                   |
| Fruit and vegetable intake (portion/day) | 2.3 (1.2, 3.5)   | 2.4 (1.2, 3.8)          | 2.1 (1.1, 3.1)        | 0.155             |
| Salt usage (%)                           |                  |                         |                       |                   |
| Adds salt                                | 66.1             | 34.4                    | 32.8                  | 0.755             |
| Does not add salt                        | 33.9             | 65.6                    | 67.2                  |                   |
| Fluid intake (L/day)                     | 1.9 (1.4, 2.5)   | 2.2 (1.7, 2.8)          | 1.4 (1.1, 1.8)        | <b>&lt; 0.001</b> |
| <b>Knowledge and attitudes</b>           |                  |                         |                       |                   |
| Knowledge                                | 13.0 (9.0, 17.0) | 13.0 (9.0, 17.0)        | 13.0 (8.0, 18.0)      | 0.663             |
| Barriers (Mean $\pm$ SD)                 | 29.8 $\pm$ 6.3   | 29.6 $\pm$ 6.3          | 30.3 $\pm$ 6.4        | 0.157             |

IQR, interquartile range; SD, standard deviation; BMI, body mass index. Data presented as median (IQR) unless stated otherwise; normally distributed data presented as mean  $\pm$  SD, Categorical data presented as % of total of group count. *P*-value derived from independent samples t test, Mann Whitney U Test or chi square test (significance set at  $p < 0.05$ ). Output category was classified as normal (fluid intake > ileostomy output) or high (fluid intake < ileostomy output).

## Country-specific differences

Most demographic variables were comparable across UK/Irish and Australian participants ( $p > 0.05$ ) except for BMI, which was significantly higher BMI in Australian respondents (29.4 [24.5, 34.3] vs 26.3 [22.6, 30.7] kg/m<sup>2</sup>;  $p = 0.001$ ). Indicators of dehydration and intake behaviours were largely similar across groups, however a greater proportion of Australians reported experiencing loose or watery output from their stoma (85.1% vs 40.0% in UK/Ireland;  $p < 0.001$ ) and estimated total fluid intake was lower in the Australian cohort (1.7 [1.3, 2.3], vs 2.0 [1.5, 2.6 L/day];  $p = 0.015$ ). No country-specific differences were observed between hydration knowledge and barriers related to hydration ( $p > 0.05$ ). An overview of participant characteristics split by country is provided as supplementary material (**Table S2**).

The number of prescribed medications reported was significantly higher in Australian participants (2.0 [1.0, 5.8] vs 2.0 [1.0, 4.0] in UK/Irish participants;  $p < 0.001$ ), however a greater proportion of UK/Ireland participants were prescribed anti-motility medication compared to that reported by Australian respondents (33.3% vs 12.0%;  $p < 0.001$ ). A lesser proportion of UK/Irish participants were prescribed anti-diabetic therapies (4.1% vs 12.0%), nutritional supplements (14.1% vs 24.0%) and laxatives (0.0% vs 4.0%) compared to participants in Australia. Country-specific differences for regular medications are summarised in supplementary **Table S3**.

## Medications

Ileostomates commonly reported taking antimotility medication (29.2%), immunosuppressants (23.8%) and anti-secretory medications (21.9%) however the proportion of those prescribed these and other medication categories were similar between output groups ( $p > 0.05$ ), except for psychiatric medications, which was greater in the high output group ( $p = 0.001$ ) (Table 3).

Table 3  
Prescribed medications in ileostomates

| Medication category        | n (%)                                                          |                                                           |                    |                            |                          | $\chi^2$<br>(df) | P-value      |
|----------------------------|----------------------------------------------------------------|-----------------------------------------------------------|--------------------|----------------------------|--------------------------|------------------|--------------|
|                            | Common examples                                                | Effect on stoma output or hydration                       | Total<br>(n = 366) | Normal output<br>(n = 244) | High output<br>(n = 122) |                  |              |
| Antimotility medications   | Loperamide, codeine phosphate                                  | ↑ Output viscosity<br>↓ Output volume [38]                | 107<br>(29.2)      | 67<br>(27.5)               | 40<br>(32.8)             | 1.12             | 0.291        |
| Immunosuppressants         | Corticosteroids, biologics                                     | ↑ Diarrhoea [39]                                          | 87<br>(23.8)       | 54<br>(22.1)               | 33<br>(27.0)             | 1.09             | 0.297        |
| Psychiatric medications    | Antidepressants, anti-anxiety medications                      | ↓ Thirst sensation<br>Alter central thermoregulation [39] | 86<br>(23.5)       | 45<br>(18.4)               | 41<br>(33.6)             | 10.40            | <b>0.001</b> |
| Anti-secretory medications | PPIs, H-2 receptor antagonists                                 | ↓ GI transit [40]                                         | 80<br>(21.9)       | 48<br>(19.7)               | 32<br>(26.2)             | 2.05             | 0.152        |
| Renally active medications | ACE-inhibitors, diuretics, ARBs, NSAIDs                        | Alter renal function [41]                                 | 35<br>(9.6)        | 20<br>(8.2)                | 15<br>(12.3)             | 1.58             | 0.209        |
| Anti-diabetic therapies    | Metformin, SGLT2 inhibitors                                    | ↑ Output volume (urine, stool) [39, 41]                   | 21<br>(5.7)        | 16<br>(6.6)                | 5 (4.1)                  | 0.91             | 0.340        |
| Oral rehydration solutions | Dioralyte                                                      | Optimise fluid absorption [42]                            | 11<br>(3.0)        | 6 (2.5)                    | 5 (4.1)                  | 0.75             | 0.387        |
| Laxatives                  | Ducolax, Movicol                                               | ↑ Output volume [43]                                      | 3<br>(0.8)         | 2 (0.8)                    | 1 (0.8)                  | 0.00             | 1.000        |
| Nutritional supplements    | Vitamin D, calcium, iron, B vitamins                           | N/A                                                       | 59<br>(16.1)       | 37<br>(15.2)               | 22<br>(18.0)             | 0.50             | 0.482        |
| Other medications          | Primarily thyroid medications, HRT, antihistamines and statins | N/A                                                       | 150<br>(41.0)      | 101<br>(41.4)              | 49<br>(40.2)             | 0.05             | 0.822        |

Data presented as frequency and % of group count,  $P$ -value derived from chi square test (significance set at  $p < 0.05$ ). Output category was classified as normal (fluid intake > ileostomy output) or high (fluid intake < ileostomy

output). GI, gastrointestinal; PPI, proton pump inhibitor; ACE, angiotensin-converting enzyme; ARB, angiotensin II receptor blocker; SGLT2, sodium-glucose co-transporter 2; NSAIDs, non-steroidal anti-inflammatory; HRT, hormone replacement therapy.

## Indicators of dehydration

Estimated ileostomy output was 1.5 (1.1, 2.0) L/day and one third (33.3%) of participants were classified as having HOS. Approximately half (48.4%) of participants were classified as dehydrated according to urine colour, however no differences were observed between normal and high output groups. Differences were observed for other indicators of dehydration, with a greater proportion of those classified as having HOS reporting loose or watery output from their stoma (58.7%, vs 44.4% in normal output group,  $p = 0.01$ ), and a greater frequency of dehydration-related symptoms ( $18.5 \pm 6.5$  vs  $16.3 \pm 5.7$ ,  $p < 0.001$ ).

## Intake behaviours

Estimated FV intake was low across the cohort (2.3 (1.2, 3.5) portions/day) and most participants (66.1%) reported adding salt to foods at the table – these intake behaviours were consistent across output groups. Estimated daily fluid intake was approximately 0.8 L lower in the HOS group (2.2 [1.7, 2.8] vs 1.4 [1.1, 1.8] L/day;  $p < 0.001$ ). Total fluid intake was predominantly from hypotonic (water, tea, coffee, diet soft drinks) fluids, which contributed 61.7% (1.3 L/day) to mean daily intake (2.1 L/day), followed by isotonic (oral rehydration solutions [ORS], sports drinks, cow's milk) fluids (27.3%; 0.6 L/day) and hypertonic (fruit juice, regular soft drinks, alcoholic beverages) fluids (11.0%; 0.2 L/day) (Fig. 1a). Caffeinated beverages made up over one third (35.9%; 0.7 L) of mean daily fluid intake (Fig. 1b). No significant differences were observed for the proportionate intakes of different fluid types between output categories.

## Hydration knowledge, barriers and relationships between variables

Hydration knowledge was low across the cohort (median score of 13 out of a maximum possible 30), with no significant differences observed when respondents were grouped by output category. Similarly, barriers to hydration (mean score of  $29.8 \pm 6.3$  out of a maximum 55) were comparable across groups. To examine the relationship between hydration knowledge, barriers, and other variables, a series of bivariate correlations were carried out, and the results are presented in Fig. 2. For example, an increasing dehydration symptom score was positively associated with more severe barriers to hydration ( $r = 0.26$ ,  $p < 0.001$ ) and negatively associated with FV intake ( $r = -0.16$ ,  $p = 0.002$ ). Significant negative correlations were observed between barriers to hydration and hydration knowledge ( $r = -0.12$ ,  $p = 0.021$ ), FV intake ( $r = -0.14$ ,  $p = 0.008$ ), total fluid intake ( $r = -0.12$ ,  $p = 0.021$ ) and hypotonic fluid intake ( $r = -0.15$ ,  $p = 0.004$ ). Of note, the number of prescribed medications was correlated with symptoms of dehydration and ileostomy output volume ( $r = 0.28$ ,  $p < 0.001$  and  $r = 0.14$ ,  $p = 0.009$ , respectively). Time since surgery was also significantly positively associated with FV intake ( $r = 0.11$ ,  $p = 0.033$ ) and hypotonic fluid intake ( $r = 0.14$ ,  $p = 0.009$ ), while isotonic fluid intake was negatively associated ( $r = -0.18$ ,  $p < 0.001$ ). Yet, when grouped into tertiles by time elapsed since surgery, the three groups were not significantly different from each other with respect to hydration-related behaviours, indicators of dehydration nor knowledge and barriers (Table 4).

The colour scale indicates the Spearman correlation coefficient between variables. Green and red shades represent positive and negative correlations respectively. The colour intensity denotes the strength of the correlation, and significance at the two-tailed level is represented by \* ( $p < 0.05$ ) or \*\* ( $p < 0.001$ ).

Table 4  
Differences for time elapsed since ileostomy surgery on intake behaviours and indicators of dehydration

| Variable                                                                                                                                                                                                                                                                                 | 0–2 years<br>(n = 135) | 3–7 years<br>(n = 107) | > 7 years<br>(n = 116) | $\chi^2$ (df) | P-value |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|------------------------|------------------------|---------------|---------|
| Fruit and vegetable intake<br>(portion/day)                                                                                                                                                                                                                                              | 2.1 (1.0, 3.1)         | 2.5 (1.4, 3.3)         | 2.6 (1.2, 4.0)         | 4.00 (2)      | 0.135   |
| Fluid intake (L/day)                                                                                                                                                                                                                                                                     | 2.1 (1.4, 2.9)         | 1.9 (1.5, 2.5)         | 1.9 (1.5, 2.5)         | 1.13 (2)      | 0.568   |
| Urinary output scale                                                                                                                                                                                                                                                                     | 44.0 (35.0, 56.0)      | 43.0 (31.8, 53.3)      | 44.0 (32.0, 54.0)      | 0.55 (2)      | 0.760   |
| Dehydration symptom score                                                                                                                                                                                                                                                                | 16.7 ± 6.1             | 17.5 ± 6.2             | 17.0 ± 5.6             | 0.50 (2)      | 0.607   |
| Urine colour                                                                                                                                                                                                                                                                             |                        |                        |                        |               |         |
| Hydrated                                                                                                                                                                                                                                                                                 | 48.9                   | 52.3                   | 52.6                   | 1.99 (2)      | 0.806   |
| Dehydrated                                                                                                                                                                                                                                                                               | 51.1                   | 47.7                   | 47.4                   |               |         |
| Ileostomy output consistency                                                                                                                                                                                                                                                             |                        |                        |                        |               |         |
| Normal                                                                                                                                                                                                                                                                                   | 50.4                   | 54.3                   | 50.9                   | 0.41 (2)      | 0.815   |
| Loose or watery output                                                                                                                                                                                                                                                                   | 49.6                   | 45.7                   | 49.1                   |               |         |
| Ileostomy output (L/day)                                                                                                                                                                                                                                                                 | 1.4 (1.1, 2.1)         | 1.5 (1.1, 2.0)         | 1.5 (1.1, 2.0)         | 0.03 (2)      | 0.984   |
| Output category                                                                                                                                                                                                                                                                          |                        |                        |                        | 3.04 (2)      | 0.218   |
| Normal                                                                                                                                                                                                                                                                                   | 64.4                   | 63.6                   | 73.3                   |               |         |
| High output                                                                                                                                                                                                                                                                              | 35.6                   | 36.4                   | 26.7                   |               |         |
| Knowledge                                                                                                                                                                                                                                                                                | 12.0 (8.0, 17.0)       | 13.0 (10.0, 17.0)      | 13.0 (8.0, 17.0)       | 0.89 (2)      | 0.640   |
| Barriers                                                                                                                                                                                                                                                                                 | 29.6 ± 6.3             | 30.1 ± 6.7             | 29.7 ± 6.0             | 0.16 (2)      | 0.854   |
| Categorical data presented as % of total or group count, normally distributed data presented as mean ± SD, non-parametric data presented as median (IQR). P-value derived from Kruskal Wallis test, one way analysis of variance, or Chi squared test (significance set at $p < 0.05$ ). |                        |                        |                        |               |         |

## Management strategies for increased stoma output

Participants were asked to describe the strategies they implemented when experiencing increased stoma output, and at what point they would seek help from a healthcare professional. This optional section was completed by  $n = 244$  participants (66.7%). Content and summative analysis of open-ended responses are presented in Table 5. Over one third (36.5%) of participants reported seeking help from a medical professional when experiencing increased output; however, most indicated that they would only do so once self-management attempts had been unsuccessful. Participants frequently reported making changes to their dietary or fluid intake, although contrasting approaches were evident (*i.e.*, increasing vs restricting intake). Other strategies included using anti-motility medications and employing methods to ease discomfort or monitor symptoms. A small proportion of participants

(4.1%) reported engaging in knowledge-seeking behaviours, including accessing peer support and online information.

Table 5

Management strategies implemented by ileostomates ( $n = 244$ ) when experiencing increased stoma output

| Main category                                                                                                          | Frequency (%) | Subcategory                         | Frequency (%) |
|------------------------------------------------------------------------------------------------------------------------|---------------|-------------------------------------|---------------|
| Fluid                                                                                                                  | 82 (33.6)     | Adjust intake (unspecified)         | 5 (2.0)       |
|                                                                                                                        |               | Increase intake                     | 22 (9.0)      |
|                                                                                                                        |               | Restrict intake                     | 9 (3.7)       |
|                                                                                                                        |               | Adjust timing of intake             | 3 (1.2)       |
|                                                                                                                        |               | Oral rehydration solutions          | 51 (20.9)     |
|                                                                                                                        |               | Soft drinks                         | 2 (0.8)       |
| Diet                                                                                                                   | 90 (36.9)     | Adjust intake (unspecified)         | 14 (5.7)      |
|                                                                                                                        |               | Restrict intake                     | 12 (4.9)      |
|                                                                                                                        |               | Salty foods                         | 4 (1.6)       |
|                                                                                                                        |               | Thickening foods <sup>a</sup>       | 60 (24.6)     |
| Seek help from medical professional                                                                                    | 89 (36.5)     | In the first instance               | 19 (7.8)      |
|                                                                                                                        |               | When self-management is ineffective | 70 (28.7)     |
| Symptom management                                                                                                     | 67 (27.5)     | Monitor output                      | 55 (22.5)     |
|                                                                                                                        |               | Monitor pain                        | 12 (4.9)      |
|                                                                                                                        |               | Rest                                | 3 (1.2)       |
|                                                                                                                        |               | Stoma appliance management          | 11 (4.5)      |
| Medication                                                                                                             | 77 (18.0)     | Anti-motility medication            | 77 (18.0)     |
| Knowledge-seeking                                                                                                      | 10 (4.1)      | Peer support                        | 2 (0.8)       |
|                                                                                                                        |               | Online support                      | 2 (0.8)       |
|                                                                                                                        |               | Unaware of management strategies    | 9 (3.7)       |
| More than one management strategy was reported by most participants; therefore, the total frequency exceeds 100%.      |               |                                     |               |
| <sup>a</sup> Thickening foods = marshmallows and other gelatine containing confectionary, white bread, mashed potatoes |               |                                     |               |

## Discussion

This study provides the first insight into the hydration-related knowledge, attitudes and practices of ileostomates across the UK, Ireland and Australia. This comprehensive single-observation survey identified a high prevalence of HOS independent of age, BMI and reason for surgery. HOS was associated with greater medication burden, shorter

postoperative duration, female sex and Australian residence. Dehydration symptoms were associated with lower FV intake, greater medication burden and increased barriers to hydration. Hydration-related knowledge was sub-optimal across the cohort, underscoring the need for improved patient education.

One third of participants were classified as experiencing HOS, consistent with the upper range of estimates reported in postoperative settings [44]. Time since surgery was shorter among participants with HOS, aligning with the view that early postoperative increases will normalise over time with intestinal adaptation [45]. However, this observation was not evident when time since surgery was examined categorically (0–2, 3–7 and > 8 years). This indicates that HOS is a persistent concern for a substantial proportion of ileostomates rather than a transient postoperative phenomenon, consistent with international consensus recommendations [17].

Sex-related differences in HOS classification were observed, with a greater proportion of females identified as having HOS despite evidence that GI transit is typically faster in males [46, 47]. This may partly reflect the intake-to-output method used to define HOS, as underreporting of intake is more commonly reported among females [48, 49]. Nearly half of participants (48.4%) deviated from normal hydration according to the urine colour chart – an accepted indicator of hydration status in general populations [50] – substantially higher than the prevalence of dehydration reported in other at-risk populations (*e.g.*, older adults) [51]. In ileostomates, darker urine colour is likely to reflect both fluid deficit and sodium depletion resulting from fluid deficit and concurrent sodium loss [16]. In this context, the prevalence of dehydration indicated by this metric is consistent with previous research reporting chronic sodium depletion in 45% of free-living ileostomates [52]. Collectively, these findings indicate that dehydration and HOS remain common long after ileostomy surgery, highlighting the need for ongoing hydration monitoring and tailored education beyond the immediate postoperative period.

Participants with HOS reported a greater number of prescribed medications, and medication burden was positively correlated with ileostomy output volume and dehydration symptoms, suggesting polypharmacy may exacerbate fluid and electrolyte imbalances. This also aligns with evidence from other clinical populations linking polypharmacy to dehydration through effects on thirst perception, GI function and renal handling [39]. These risks are likely amplified in ileostomates, where physiological capacity for fluid reabsorption is compromised by loss of colonic function [53]. Although most medications did not differ by output category, psychiatric medications were more prevalent among those with HOS, which may reflect either medication-related effects on hydration and GI function [54], or increased psychological burden among those experiencing increased output [55]. Marked geographical differences in prescribing practices were observed, with Australian participants reporting a higher number of medications but lower prescription of antimotility agents. As antimotility agents can reduce ileostomy output volume by ~ 17% [56] and increase effluent viscosity [38], these differences may have contributed to the higher prevalence of HOS observed in Australian participants. Such findings underscore the potential clinical impact of prescribing norms and highlight antimotility medications as a modifiable factor in managing stoma output.

The interaction between medication burden and hydration outcomes in this cohort cannot be considered in isolation from fluid intake behaviours. Australian participants reported significantly lower daily fluid intake compared with their UK and Ireland counterparts (1.7 (1.3, 2.3), vs 2.0 (1.5, 2.6) L/day, despite data collection occurring during the summer months for Australian participants and winter months for UK/Ireland participants. Given the increased hydration demands associated with warmer temperatures [57], this finding suggests that healthcare system factors may have a greater influence on fluid intake than climate alone. However, the relatively smaller Australian sample should be considered when interpreting between-country comparisons. Mean daily fluid

intake across the entire cohort (~ 1.9 L/day) was lower compared to intakes observed in non-clinical populations in the UK (2.2 L/day) and Australia (2.3 L/day) [58, 59]. For individuals with moderately elevated output (1.0–1.5 L/day), clinical practice advises fluid restriction of < 1.5 L/day to minimise further increases in output [16], thus lower reported fluid intakes in this cohort may be indicative of adherence to advice. It is important to acknowledge that such recommendations are largely based on expert opinion rather than clinical evidence [60]. Moreover, in the absence of appropriate fluid and electrolyte replacement, such restriction may inadvertently exacerbate dehydration symptoms. Fluid intake in this cohort was predominantly derived from hypotonic beverages, contrasting clinical guidelines [22] and empirical evidence [61, 62] which favours the use of isotonic solutions for optimal sodium and water absorption in HOS management. The absence of differences in fluid type consumption between output groups, and low uptake of ORS during episodes of high output (~ 20%), suggests limited translation of hydration guidance into everyday practice. Indeed, hydration knowledge scores of ileostomates were lower compared to that of healthy adults (13.0 vs 15.5 score out of a possible 30) [27], suggesting reduced hydration literacy in this high-risk population. These findings highlight suboptimal hydration practices may be driven by limited knowledge. Therefore, improved education is essential to bridge the gap between expert guidance, clinical evidence and real-world behaviours to reduce dehydration risk.

Postoperatively, ileostomates are often advised to limit FV intake to minimise stoma output [63]. However, FV intake remained low regardless of time since surgery, consistent with observations in earlier ileostomy populations [21]. Median FV intake in this cohort was 2.3 portions/day, considerably below population averages in the UK and Australia (~ 3.3 and ~ 4.2 portions/day, respectively) [64, 65]. Lower FV intake was correlated with greater dehydration symptoms, which may reflect more severe dietary restriction in those experiencing hydration difficulties. This relationship may also be explained by the contribution of FV to fluid intake and hydration status [66], therefore it could be inferred that FV restriction in this cohort may worsen dehydration symptoms by reducing intake of water rich foods. The persistence of FV restriction may be further compounded by hydration-related barriers, which were notably higher in this cohort (mean score 29.8 out of 55) compared with those reported in healthy populations (mean score 13.9 out of 90) [27]. Coupled with the low hydration knowledge observed, these findings suggest that long-term FV restriction may reflect ongoing gaps in knowledge translation and self-management, with potential implications for hydration status and dietary adequacy.

Ileostomates are routinely advised to increase dietary salt intake to compensate for sodium losses [10, 16, 67, 68], yet evidence for the health implications of adhering to this advice for this group is limited. In this cohort, ~ 66% of participants reported adding salt to foods, nearly double the frequency reported in general populations in Australia (34%) and treble UK values (23%) [69, 70], suggesting comparatively high adherence to ileostomy-specific dietary guidance. However, salt use did not differ by output category, indicating that discretionary salt addition alone may be insufficient to mitigate dehydration risk. While salt supplementation remains a common component of ileostomy care, the absence of an association with hydration outcomes in this cohort, alongside established cardiovascular risks associated with high salt intake [71], highlights the need to re-evaluate the validity and framing of this advice.

Content analysis demonstrated variable adherence to recommended HOS management strategies, aligning with low hydration knowledge scores observed quantitatively. Knowledge-seeking behaviours were uncommon, with minimal engagement with peer or online support. Although sources of advice were not explored directly, dietary advice – presumably including output management strategies – is primarily provided by dietitians and stoma nurses [72]. In this cohort, over one third of participants (36.5%) reported seeking support from a healthcare professional, which is broadly consistent with the proportion of hospital readmissions relating to HOS [44],

suggesting that professional input may often be accessed reactively rather than preventatively. Many ileostomates appeared to rely predominantly on self-management, consistent with previous qualitative findings [73].

## Conclusion

To our knowledge, this is the first multinational study to examine hydration knowledge, barriers and self-management behaviours among people living with an ileostomy. Dehydration and HOS were highly prevalent and were associated with potentially modifiable factors, including medication burden, intake behaviours, perceived barriers and suboptimal hydration knowledge. These findings support the need for routine hydration monitoring, consistent patient education and proactive long-term follow-up in ileostomy care.

## Declarations

## Competing interests

There are no competing interests to declare.

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## Author Contribution

Funding: JD; Study conception and design: N.M., H.McC. P.D., and C.I.R.G.; Supervision: C.I.R.G., L.K.P, J.D., E.E.A.S. and E.J.R.; Recruitment: N.M., H.McC., M.V. and N.N.; Data Analyses: N.M.; Writing – original draft preparation: N.M. All authors read and approved the final manuscript.

## Data Availability

Anonymised data supporting the findings of this study are available from the corresponding author upon reasonable request. Restrictions apply to the availability of these data to protect participant confidentiality and in accordance with ethical approval conditions.

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## Figures

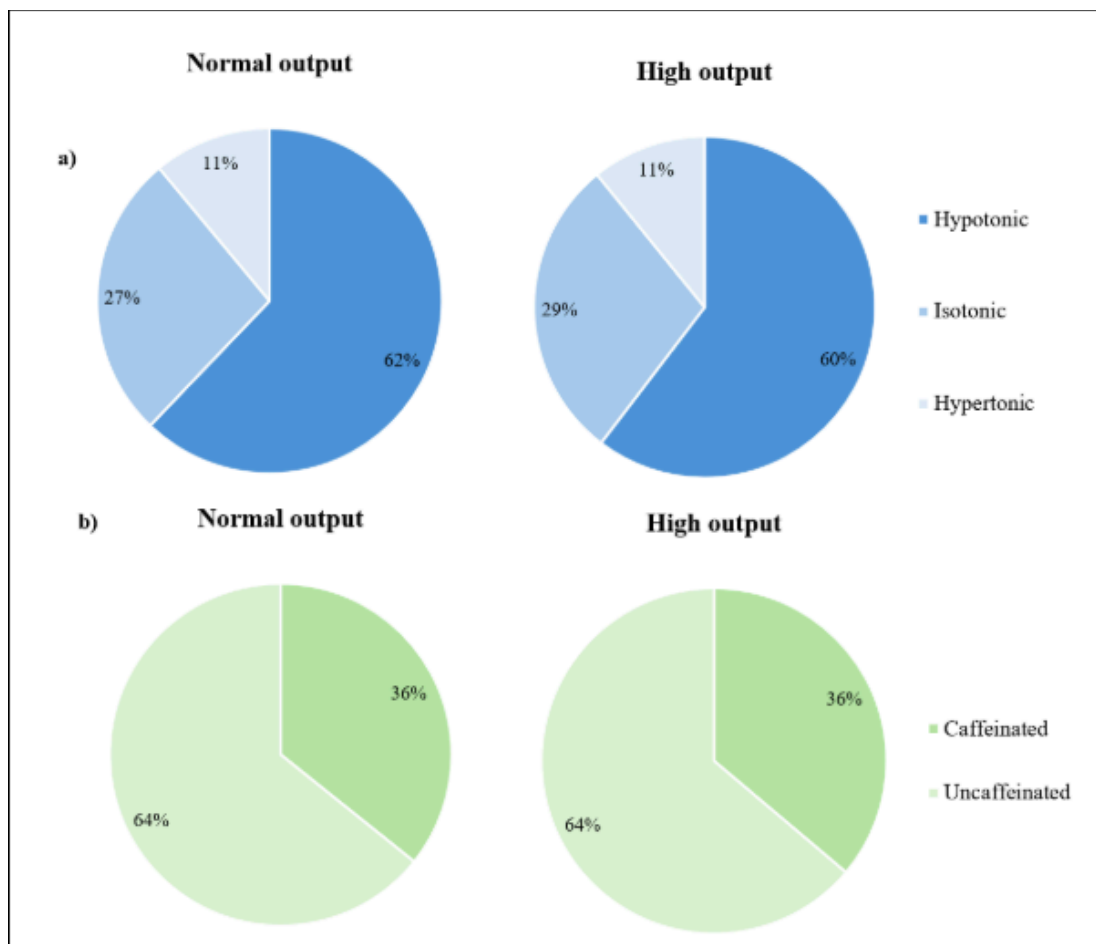


**Figure 1**

Contribution to mean estimated daily fluid intake (L) from **a)** hypotonic, isotonic and hypertonic fluids; **b)** caffeinated and non-caffeinated beverages in ileostomates classified as having a normal ( $n=244$ ) and high output ( $n=122$ ).



**Figure 2**

Correlation between indicators of dehydration, intake behaviours, hydration knowledge and related barriers.

The colour scale indicates the Spearman correlation coefficient between variables. Green and red shades represent positive and negative correlations respectively. The colour intensity denotes the strength of the correlation, and significance at the two-tailed level is represented by \* ( $p < 0.05$ ) or \*\* ( $p < 0.001$ ).

## Supplementary Files

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