



Mitchell, A., England, C. Y., & Atkinson, C. (2020). Provision of dietary advice for people with an ileostomy: A survey in the UK and Ireland. *Colorectal Disease*. <https://doi.org/10.1111/codi.15268>

Publisher's PDF, also known as Version of record

License (if available):  
CC BY

Link to published version (if available):  
[10.1111/codi.15268](https://doi.org/10.1111/codi.15268)

[Link to publication record in Explore Bristol Research](#)  
PDF-document

This is the final published version of the article (version of record). It first appeared online via BMC at <https://doi.org/10.1111/codi.15268> . Please refer to any applicable terms of use of the publisher.

## University of Bristol - Explore Bristol Research

### General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available: <http://www.bristol.ac.uk/pure/user-guides/explore-bristol-research/ebr-terms/>



# European Colorectal Congress

29 November – 2 December 2020, St.Gallen, Switzerland

Sunday, 29 November 2020

## MASTERCLASS

### Introduction & course objectives

Michel Adamina, Winterthur, CH

### Myths and facts about oral antibiotics, bowel preparation, and timing of iv antibiotics to reduce surgical site infection

Frédéric Ris, Geneva, CH

### Management of colorectal GIST – all you should know from diagnosis to handling recurrences

Paris Tekkis, London, UK

### Do and don't in taTME surgery – a decade of experience explained

Roel Hompes, Amsterdam, NL

### What your pathologist can do for you: from standard margins recommendations to molecular pathology, liquid biopsies, and the microbiome

Phil Quirke, Leeds, UK

### Prehabilitation, patient blood management, frailty index – welcome addition or resource wasting

Des Winter, Dublin, IE

### Selective use of neoadjuvant and adjuvant radiotherapy for rectal cancer

Chris Cunningham, Oxford, UK

### Handling large rectal adenoma and malignant polyps

Willem Bemelman, Amsterdam, NL

### All techniques to avoid staple line intersections in colorectal surgery

Antonino Spinelli, Milano, IT

### Management of pelvic sepsis after colorectal / coloanal anastomosis and oncological outcomes of the GRECCAR 5 trial

Quentin Denost, Bordeaux, FR

### Best practices in colostomy construction and repair of parastomal hernia

Eva Angenete, Göteborg, SE

### The EBSQ Coloproctology Examination

Michel Adamina, Winterthur, CH

### Wrap-up

Michel Adamina, Winterthur, CH

Sunday, 29 November 2020

## COURSE OF PROCTOLOGY

### Introduction & course objectives

Bruno Roche, Geneva, CH

### Complex pelvic fistula revisited: established wisdom and innovative approaches

Alexander Herold, Mannheim, DE

### Obstretical trauma: assessment, timing and options to repair

Patrick Hohlfeld, Lausanne, FR

### The painful bottom – Proctalgia beyond the classical abscess, fissures, and hemorrhoids

Bruno Roche, Geneva, CH

### Sexually transmitted diseases in proctology

Karel Skala, Geneva, CH

### Anorectal trauma and foreign bodies

Richard Cohen, London, UK

### Pilonidal sinus – strategies and outcomes

Frédéric Ris, Geneva, CH

### Fecal incontinence: investigations and conservative treatment

Beatrice Salvioli, Milano, IT

### Fecal incontinence: neuromodulation and interventional options

Joan Robert-Yap, Geneva, CH

### The pelvic floor revealed: transperineal / transvaginal / transanal repairs explained

Bruno Roche, Geneva, CH

### The pelvic floor revealed: investigations and pelvic floor therapy

Jacqueline de Jong, Bern, CH

### Obstructed defecation and IBS: investigations, differential diagnosis, and treatment strategies

Daniel Pohl, Zurich, CH

### Obstructed defecation: surgical options

André d'Hoore, Leuven, BE

### Wrap-up

Alexander Herold, Mannheim, DE

Monday, 30 November 2020

## SCIENTIFIC PROGRAMME

### Opening and welcome

Jochen Lange, St. Gallen, CH

### Is cancer an infectious disease: role of the microbiome

Philip Quirke, Leeds, UK

### Ethical considerations in crisis – lessons from Covid-19

Omar Faiz, London, UK

### SATELLITE SYMPOSIUM Medtronic

### Prophylactic mesh in colorectal surgery

René H. Fortelny, Wien, AT

### Lars Pahlman lecture: Extending the limits of liver surgery

Markus Büchler, Heidelberg, DE

### Multimodal approaches to colorectal liver metastases

Mohammed Abu Hilal  
Brescia, IT

### SATELLITE SYMPOSIUM Ethicon

### Urogenital dysfunction in patients treated for rectal cancer – what do we know and what can we do?

Eva Angenete, Göteborg, SE

### Hemorrhoids – new options and time-tested solutions

Alexander Herold,  
Mannheim, DE

### Anal pain and emergency proctology: what every surgeon should know & do

Richard Cohen, London, UK

### All you need to know about anorectal fistula

Bruno Roche, Genève, CH

### Strategies and outcomes for obstructive cancers of the colon and rectum

Willem Bemelman,  
Amsterdam, NL

Tuesday, 1 December 2020

## BREAKFAST SYMPOSIUM Karl Storz

### Lessons learned along the robotic learning curve: a video guide for colorectal surgeons

Jim Khan, Portsmouth, UK



### EAES presidential lecture: Strategies for lifelong learning and implementation of new technologies

Andrea Pietrabissa, Pavia, IT

### SATELLITE SYMPOSIUM Intuitive

### A journey in global surgery – why getting out of the comfort zone

Raffaele Rosso, Lugano, CH

### Enhanced recovery pathways reloaded – a practical guide to success

Roberto Persiani, Roma, IT

### Cancer at the extremes of age: are there any differences in handling youngsters and seniors

Des Winter, Dublin, IE

### Management pearls for early rectal cancer

Roel Hompes, Amsterdam, NL

### Ventral rectopexy: indications, tricks of the trade, and long-term results

Chris Cunningham, Oxford, UK

### SATELLITE SYMPOSIUM BBraun

### Total neoadjuvant therapy for colon and rectum cancers

Ronan O'Connell, Dublin, IE

### Randomized trial evaluating chemotherapy followed by pelvic reirradiation vs chemotherapy alone as preoperative treatment for locally recurrent rectal cancer (GRECCAR 15)

Quentin Denost, Bordeaux, FR

### Timeline of surgery following neoadjuvant radiotherapy – balancing morbidity and efficacy

Torbjörn Holm, Stockholm, SE

### Poster award

Michel Adamina, Winterthur, CH

Wednesday, 2 December

## Place and outcome of total colectomy in the surgical armamentarium

Neil Mortensen, Oxford, UK

## Kono S anastomosis and over the valve stricturoplasties: hope for better outcomes

André D'Hoore, Leuven, BE

## New drugs, old fears: state of the art management of IBD patients

Gerhard Rogler, Zurich, CH

## SATELLITE SYMPOSIUM Takeda

## Do resection of the mesentery in Crohn's & appendectomy in ulcerative colitis alter the course of disease

Christianne Buskens,  
Amsterdam, NL

## The septic abdomen: getting out of misery and closing the case

Marja Boermeester,  
Amsterdam, NL

## Management strategies for patients with advanced colorectal cancers

Paris Tekkis, London, UK

## Anastomotic leak in colorectal surgery: insights, perspectives, and practical strategies

Antonino Spinelli, Milano, IT

## Closing words

Michel Adamina, Winterthur, CH

The publication of this advertisement does not constitute endorsement by the society, publisher, or Editors, and is unrelated to the content that follows

Information & Registration

[www.colorectalsurgery.eu](http://www.colorectalsurgery.eu)

# Provision of dietary advice for people with an ileostomy: a survey in the UK and Ireland

A. Mitchell , C. England  and C. Atkinson 

National Institute for Health Research Bristol Biomedical Research Centre, University Hospitals Bristol and Weston NHS Foundation Trust, University of Bristol, Bristol, UK

Received 2 April 2020; accepted 30 June 2020; Accepted Article online 15 July 2020

## Abstract

**Aim** The aim was to explore whether people with an ileostomy in the UK and Ireland receive the dietary advice they require.

**Method** An online survey with multiple-choice questions asked people with an ileostomy about the dietary advice they received and would have preferred to receive. Participants were recruited via websites of the Ileostomy and Internal Pouch Association and Crohn's and Colitis UK and via social media. People with a current ileostomy, age 16 years or over, and living in the UK or Ireland were eligible for inclusion. Responses were analysed using descriptive statistics.

**Results** In all, 291 eligible responses were received and included in the analysis; 201 (69%) received advice on diet for their ileostomy from a healthcare professional or the internet. Of the 90 who did not receive dietary advice, 82 (91%) would have liked advice. Stoma nurses were the most common source of dietary advice (55%), but many other sources were frequently reported. Most (62%) felt that at least some dietary

advice they received was conflicting. Over half (55%) felt anxious about managing their diet with a new ileostomy, 39% were confused, and 31% frustrated. Of 291 respondents, 29% received advice from a dietitian compared to 60% who would have preferred advice from a dietitian.

**Conclusion** Many people undergoing ileostomy surgery do not receive the dietary advice and support they require. Healthcare professionals working with people with an ileostomy should be mindful they are often anxious about their diet and require clear and consistent dietary advice and support.

**Keywords** diet, ileostomy, stoma

### What does this paper add to the literature?

This is the first study to describe sources and delivery of dietary advice to people with an ileostomy in the UK and Ireland, and their attitudes, feelings and preferences towards dietary advice and management. Findings show that many people with an ileostomy do not receive the dietary advice and support they require.

## Introduction

In the UK, > 21 000 people have surgery to create a stoma annually [1]. Ileostomies are a type of stoma creating a diversion of the gastrointestinal tract from the ileum through an opening in the abdomen. Common complications include high stoma output and blockage, and unpleasant symptoms such as wind and odour [2,3]. Dietary advice may be provided to help manage these issues [4]. Common recommendations are to avoid specific fruit, nuts and vegetables high in insoluble fibre, to prevent obstruction [5]. A diet high in

white, starchy carbohydrates and low in fibre is recommended to thicken loose output [4,6]. Lists of foods and drinks that may cause wind and odour are often provided [7]. People with an ileostomy frequently modify their diet and report that dietary implications of their ileostomy affect daily life [8–10]. Unfortunately, although dietary advice is important to ileostomists [11], evidence to inform practice is limited [12] and what may be problematic for some may pose no or little issue for others [2].

A qualitative study of six people with an ileostomy and Crohn's disease in the UK suggested dietary advice was insufficient, could be confusing or conflicting, and advice varied between health professions [10]. In a Swedish survey of ostomy patients' perceptions of quality of care, 95% of ileostomists believed information on

\*Correspondence to: A. Mitchell RD, MClInRes, NIHR Bristol Biomedical Research Centre (Nutrition Theme), University Hospitals Bristol Education and Research Centre, Upper Maudlin Street, Bristol BS2 8AE, UK.  
E-mail: Alexandra.Mitchell@bristol.ac.uk

diet was important; however, 36% (14/39) said information received was not satisfactory [11]. More recently, a survey of 425 ostomates (ileostomy, colostomy or urostomy) in the UK reported that 67% received information, advice or support about diet after stoma surgery, while 30% did not but would have liked to [13]. Of those who received dietary advice, 82% found this useful. The results were not reported separately by stoma type. Studies to date suggest improvement is needed in the provision of dietary advice to people with an ileostomy, but details of where dietary advice comes from, how it is provided and the extent to which patient need is unmet have not yet been described.

The aims of this study were to explore (i) the proportion of ileostomists who received dietary advice for ileostomy management; (ii) source(s) of advice; (iii) attitudes towards advice; and (iv) perceived need for dietary advice.

## Method

An online multiple-choice survey was developed in collaboration with healthcare professionals (HCPs) and people with an ileostomy (Appendix S1). A draft questionnaire was created by the authors, including two dietitians, and sent to a colorectal surgeon, stoma nurse and dietitian for feedback on content and wording. The revised questionnaire was put into an online format and three members of a patient and public involvement (PPI) group, who all had an ileostomy, took part in cognitive interviews with AM to assess and increase the face validity of the questions [14]. PPI members spoke out loud their thoughts while completing the survey, and AM asked probing questions to gain further insight. As well as cognitive interviews, PPI members were asked for their views on the relevance of questions and important aspects they felt were not captured. Based on the first two interviews, the wording and layout of several questions were changed to increase clarity, additional response options were provided for some questions, and questions were added to ensure all important experiences in relation to dietary advice were captured. The updated survey was used in the third interview and only a few minor changes were made after this.

The cross-sectional survey was administered using Online Surveys (<https://www.onlinesurveys.ac.uk>). The survey link was available on the websites of the Ileostomy and Internal Pouch Association (November 2018–December 2019) and Crohn's and Colitis UK (September 2019–December 2019). The open survey was promoted on social media inviting eligible people to

participate. Eligibility criteria were age  $\geq 16$  years and current ileostomy. Responses from outside the UK and Ireland were excluded. The first page provided participant information and stated that continuing to the following pages would be taken as agreement to participate. Where appropriate, survey items were mandatory. Questions relating to dietary advice received were only displayed if the participant responded 'yes' when asked if they had received dietary advice. Respondents were able to review and change responses prior to submission.

A convenience sample anonymously responded to the survey. Responses were downloaded to IBM SPSS v24.0 (IBM Corp., Armonk, New York, USA) for analysis. Data from respondents meeting all inclusion criteria were analysed using descriptive statistics to provide frequencies of responses to each question. If there was a discrepancy between the total number of people reporting a source of dietary advice and the total number of people reporting details associated with advice from that source in a related sub-question, the highest total number of responses was used as the overall frequency for that source. For example, where 150 people selected that they received advice from a stoma nurse but 159 responded to a sub-question about the format of dietary advice received from a stoma nurse, then the total number of people receiving advice from a stoma nurse was assumed to be 159.

A comparison is presented between how dietary advice was received and how respondents would have preferred to receive advice. Responses may differ according to the length of time since having a stoma placed. Therefore, we conducted a *post hoc* comparison between those who had been living with an ileostomy for  $< 6$  months *vs*  $> 10$  years.

Ethical approval was obtained from the Faculty of Health Sciences Research Ethics Committee at the University of Bristol (reference number 73467). The survey has been reported in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES; Appendix S1) [15].

## Results

The survey was completed by 329 respondents. Thirty-eight did not meet inclusion criteria (30 outside the UK and Ireland; eight without current ileostomy) leaving a final sample of 291. Demographics and clinical characteristics of included respondents are shown in Table 1. Most were women (72.5%), age 45–74 years (64.9%), had an ileostomy due to ulcerative colitis (37.8%) and had an ileostomy for  $> 10$  years (23.7%) or  $< 6$  months (21.3%).

**Table 1** Respondent characteristics ( $n = 291$ ).

	<i>n</i> (%)
Gender	
Female	211 (72.5)
Male	80 (27.5)
Age (years)	
16–24	8 (2.7)
25–34	25 (8.6)
35–44	50 (17.2)
45–54	65 (22.3)
55–64	65 (22.3)
65–74	59 (20.3)
75 or over	19 (6.5)
Region	
South East England	54 (18.6)
South West England	42 (14.4)
Scotland	26 (8.9)
West Midlands	25 (8.6)
East Midlands	24 (8.2)
North West England	24 (8.2)
London	23 (7.9)
East of England	18 (6.2)
Wales	17 (5.8)
Yorkshire and Humber	17 (5.8)
North East England	10 (3.4)
Republic of Ireland	8 (2.7)
Northern Ireland	3 (1.0)
Condition requiring ileostomy	
Crohn's disease	52 (17.9)
Ulcerative colitis	110 (37.8)
Cancer	57 (19.6)
Trauma	7 (2.4)
Functional bowel disorder	14 (4.8)
Other	50 (17.2)
Don't know	1 (0.3)
Length of time with ileostomy	
< 6 months	62 (21.3)
6 months up to 1 year	29 (10.0)
1–2 years	46 (15.8)
3–5 years	48 (16.5)
6–10 years	37 (12.7)
Over 10 years	69 (23.7)
Elective <i>vs</i> emergency surgery	
Elective	159 (54.6)
Emergency	125 (43.0)
Not sure	7 (2.4)
Permanent <i>vs</i> temporary ileostomy	
Permanent	208 (71.5)
Temporary	53 (18.2)
Not sure	30 (10.3)
Member of Ileostomy and Internal Pouch Association	115 (39.5)

**Table 2** Ileostomy-related problems.

Since having an ileostomy, have any of the following caused you difficulties?	<i>n</i> (%)
Very loose or watery stoma output	252 (86.6)
Wind or gas	206 (70.8)
High volume of stoma output	182 (62.5)
Increased odour from stoma bag	128 (44.0)
Pain in your bowel or stoma	125 (43.0)
Blockage or obstruction of the bowel or stoma	124 (42.6)
None of the above	5 (1.7)

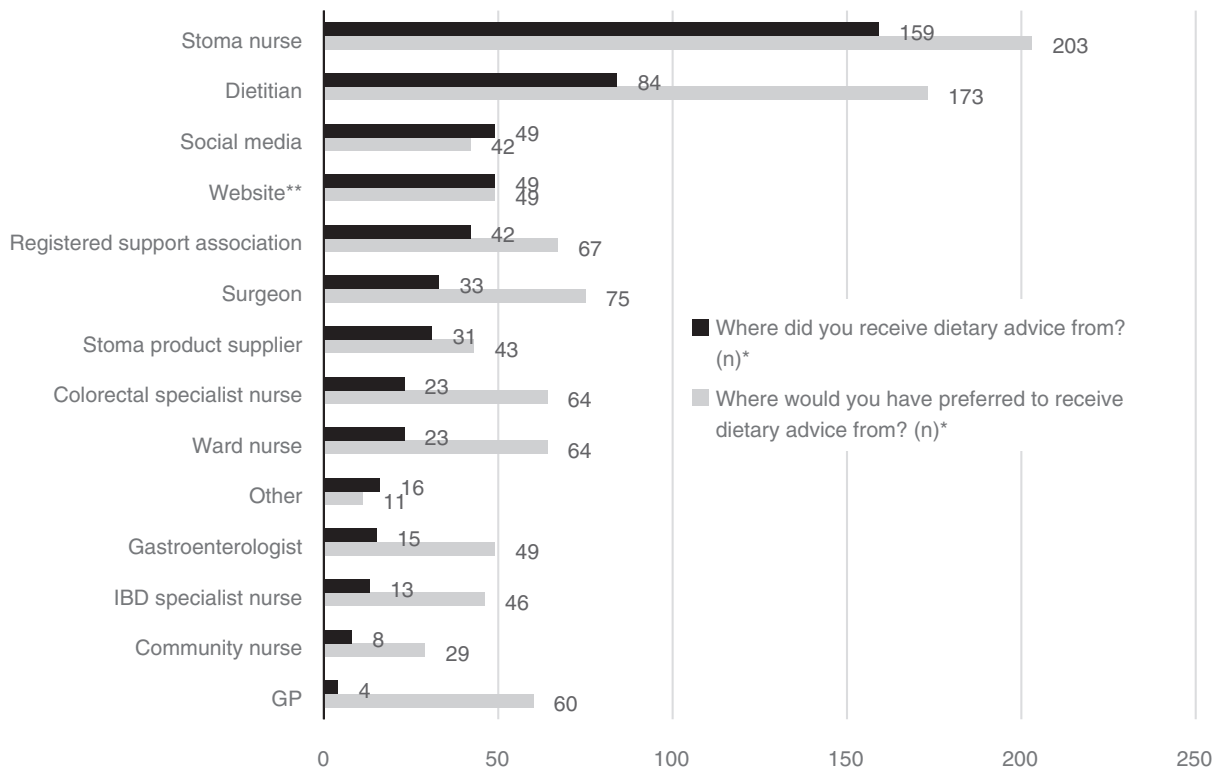
### Ileostomy-related problems

Table 2 shows the prevalence of ileostomy-related problems. The most common issue was very loose/watery output, followed by wind or gas, and high output. When asked whether they thought improved dietary advice could have prevented any of these issues, 66 (22.7%) answered that it 'definitely' could have and 136 (46.7%) thought it 'possibly' could.

### Provision of dietary advice

Two hundred and one of the 291 respondents (69.1%) received dietary advice for their ileostomy either from an HCP or the internet. Of the 90 who did not receive dietary advice, 82 (91.1%) would have liked to. Figure 1 shows the number of respondents who received dietary advice, from a range of sources, compared to preferred sources for dietary advice. The most common source was the stoma nurse (54.6% of all respondents), and this was also the most preferred source (69.8%). However, 59.5% of respondents wanted dietary advice from a dietitian while only 28.9% received this.

Table 3 shows how respondents received and would have preferred to receive dietary advice. When advice was received from HCPs, it was most commonly verbal (median 86%, range 79%–100%), while printed information from HCPs was less common (median 29%, range 0%–69%). Preferences showed that more respondents would like to receive dietary advice from HCPs in printed format (median 63%, range 41%–86%). Few wanted advice from HCPs to be online ( $\leq 24\%$ ). Conversely, when advice was received from a registered support association or stoma product supplier it was usually printed material (64.3% or 67.7%) or online (66.7% or 48.4%). There were slight preferences for information to be provided as printed material (59.7% and 65.1%), but online was also popular ( $\approx 58\%$ ).



**Figure 1** Sources of dietary advice for people with ileostomy (GP, general practitioner; IBD, inflammatory bowel disease). \*Maximum number of responses to any question indicating that dietary advice was received/would have been preferred from the specified source. \*\*Not including that of registered support associations or stoma product suppliers.

Table 4 shows responses regarding actual timing of dietary advice and preferred timing. When dietary advice was received from HCPs, it was mostly provided during hospital admission (e.g. of those who received advice from the stoma nurse, dietitian or surgeon, 79.0%, 63.0% and 72.7% respectively received advice at this time). Some received advice from the stoma nurse or dietitian after discharge (36.2% and 49.3%) and some before surgery (29.7% and 11.0%). Respondents indicated that more would have liked to receive dietary advice from HCPs before surgery and after discharge. Although the greatest preference was to receive dietary advice from the stoma nurse or dietitian while in hospital (72.3% and 74.2%), approximately half would have liked dietary advice from the stoma nurse or dietitian before surgery and after discharge (range 45%–58%). Most dietary advice from support associations and stoma product suppliers was received after discharge (89.2% and 82.8%), in line with respondent preference (83.3% and 90.0%).

Of the 201 respondents who received dietary advice, 124 (61.7%) felt that some or all of this advice was conflicting. Ninety-three (75.0%) of these reported they received advice from more than one source. When asked

about the type of dietary advice received, 178 (88.6%) reported receiving advice to change the types of food they ate, i.e. adding/removing specific foods. One hundred and five (52.2%) were advised how to prepare certain foods, e.g. boil carrots instead of eating raw, and 155 (77.1%) were advised how to eat certain foods, e.g. chew well. Most did not receive advice on weight management (146 of 201, 72.6%). Of those who did receive advice about their weight, 36 (65.5%) were advised to gain weight *vs* six (10.9%) advised to lose weight. One hundred and seventy-nine of the 201 respondents (89.1%) who received dietary advice made changes based on this advice. Of these, 108 (60.3%) believed this helped manage their ileostomy.

Respondents were asked to select up to three feelings, from a list provided, that best described their experience of managing diet with a new ileostomy (Fig. 2). Over half felt anxious (55.0%), and around a third felt confused or frustrated (39.2% and 31.3%). In contrast, < 20% felt confident or well supported (18.9% and 13.4%).

Around three-quarters of participants responded 'fairly' or 'slightly' when asked about their confidence in/usefulness of/satisfaction with dietary advice

**Table 3** Format of dietary advice for people with an ileostomy.

		How was dietary advice provided? Select all that apply, <i>n</i> (%)			
		Printed	Verbal	Online	Other
Stoma nurse	Actual* ( <i>n</i> = 159)	102 (64.2)	126 (79.2)	3 (1.9)	0 (0)
	Preferred† ( <i>n</i> = 203)	167 (82.3)	128 (63.1)	47 (23.2)	3 (1.5)
Dietitian	Actual* ( <i>n</i> = 84)	53 (63.1)	68 (81.0)	2 (2.4)	1 (1.2)
	Preferred† ( <i>n</i> = 173)	148 (85.5)	112 (64.7)	32 (18.5)	5 (2.9)
Social media	Actual* ( <i>n</i> = 49)	3 (6.1)	1 (2.0)	45 (91.8)	1 (2.0)
	Preferred† ( <i>n</i> = 42)	10 (23.8)	3 (7.1)	36 (85.7)	1 (2.4)
Website‡	Actual* ( <i>n</i> = 49)	6 (12.2)	2 (4.1)	43 (87.8)	1 (2.0)
	Preferred† ( <i>n</i> = 49)	22 (44.9)	5 (10.2)	32 (65.3)	2 (4.1)
Registered support association	Actual* ( <i>n</i> = 42)	27 (64.3)	4 (9.5)	28 (66.7)	1 (2.4)
	Preferred† ( <i>n</i> = 67)	40 (59.7)	22 (32.8)	39 (58.2)	3 (4.5)
Surgeon	Actual* ( <i>n</i> = 33)	1 (3.0)	33 (100)	0 (0)	0 (0)
	Preferred† ( <i>n</i> = 75)	40 (53.3)	55 (73.3)	7 (9.3)	1 (1.3)
Stoma product supplier	Actual* ( <i>n</i> = 31)	21 (67.7)	2 (6.5)	15 (48.4)	0 (0)
	Preferred† ( <i>n</i> = 43)	28 (65.1)	9 (20.9)	25 (58.1)	2 (4.7)
Colorectal specialist nurse	Actual* ( <i>n</i> = 23)	14 (60.9)	19 (82.6)	0 (0)	0 (0)
	Preferred† ( <i>n</i> = 64)	46 (71.9)	49 (76.6)	13 (20.3)	2 (3.1)
Ward nurse	Actual* ( <i>n</i> = 23)	5 (21.7)	20 (87.0)	0 (0)	0 (0)
	Preferred† ( <i>n</i> = 64)	26 (40.6)	51 (79.7)	5 (7.8)	0 (0)
Other	Actual* ( <i>n</i> = 9)	4 (44.4)	2 (22.2)	3 (33.3)	3 (33.3)
	Preferred† ( <i>n</i> = 11)	8 (72.7)	3 (27.3)	4 (36.4)	2 (18.2)
Gastroenterologist	Actual* ( <i>n</i> = 14)	4 (28.6)	12 (85.7)	0 (0)	1 (7.1)
	Preferred† ( <i>n</i> = 48)	30 (62.5)	33 (68.8)	7 (14.6)	1 (2.1)
IBD specialist nurse	Actual* ( <i>n</i> = 13)	9 (69.2)	11 (84.6)	0 (0)	0 (0)
	Preferred† ( <i>n</i> = 46)	30 (65.2)	35 (76.1)	7 (15.2)	2 (4.3)
Community nurse	Actual* ( <i>n</i> = 8)	0 (0)	8 (100)	0 (0)	0 (0)
	Preferred† ( <i>n</i> = 29)	14 (48.3)	28 (96.6)	7 (24.1)	0 (0)
GP	Actual* ( <i>n</i> = 3)	0 (0)	3 (100)	0 (0)	0 (0)
	Preferred† ( <i>n</i> = 60)	35 (58.3)	40 (66.7)	7 (11.7)	0 (0)

GP, general practitioner; IBD, inflammatory bowel disease.

\*How was dietary advice provided?

†How would you have liked dietary advice to be provided?

‡Not including that of registered support associations or stoma product suppliers.

(Table 5). One hundred and eleven (55.2%) indicated only 'some of it' made sense, while 79 (39.3%) said it made sense and 11 (3.8%) that it did not make sense.

### Inpatient care

Whilst in hospital following ileostomy surgery, 35 (12.0%) received a 'special menu' (assumed to be anything other than the standard hospital menu), while 139 (47.8%) would have preferred a special menu. Seventy-four (25.4%) received verbal advice on making choices from the standard hospital menu, while 151 (51.9%) would have preferred such advice. One hundred and twenty-nine (44.3%) respondents did not receive any support with meal choices (i.e. a special

menu or verbal advice) when they needed it, and only 40 (13.7%) felt they received sufficient support.

### Subgroup analysis

Sixty-two respondents (21.3%) had been living with an ileostomy for < 6 months (group 1) and 69 (23.7%) for > 10 years (group 2). More people in group 1 than group 2 reported receiving any dietary advice (79.0% *vs* 52.2%), and they were more likely to report receiving dietary advice from a stoma nurse (71.0% *vs* 31.9%) and via social media (21.0% *vs* 8.7%). Over half in both groups who received dietary advice reported some of it to be conflicting (group 1, 65.3%; group 2, 55.6%). More people in group 1 than group 2 reported they

**Table 4** Timing of dietary advice for people with an ileostomy.

		When was dietary advice provided? Select all that apply, <i>n</i> (%)		
		Before surgery	In hospital	After discharge
Stoma nurse	Actual* ( <i>n</i> = 138)	41 (29.7)	109 (79.0)	50 (36.2)
	Preferred† ( <i>n</i> = 195)	113 (57.9)	141 (72.3)	108 (55.4)
Dietitian	Actual* ( <i>n</i> = 73)	8 (11.0)	46 (63.0)	36 (49.3)
	Preferred† ( <i>n</i> = 155)	69 (44.5)	115 (74.2)	85 (54.8)
Social media	Actual* ( <i>n</i> = 41)	10 (24.4)	6 (14.6)	37 (90.2)
	Preferred† ( <i>n</i> = 31)	13 (41.9)	12 (38.7)	29 (93.5)
Website‡	Actual* ( <i>n</i> = 36)	7 (19.4)	3 (8.3)	33 (91.7)
	Preferred† ( <i>n</i> = 43)	19 (44.2)	19 (44.2)	36 (83.7)
Registered support association	Actual* ( <i>n</i> = 37)	6 (16.2)	6 (16.2)	33 (89.2)
	Preferred† ( <i>n</i> = 54)	21 (38.9)	19 (35.2)	45 (83.3)
Surgeon	Actual* ( <i>n</i> = 33)	9 (27.3)	24 (72.7)	8 (24.2)
	Preferred† ( <i>n</i> = 62)	35 (56.5)	40 (64.5)	21 (33.9)
Stoma product supplier	Actual* ( <i>n</i> = 29)	7 (24.1)	4 (13.8)	24 (82.8)
	Preferred† ( <i>n</i> = 40)	11 (27.5)	11 (27.5)	36 (90.0)
Colorectal specialist nurse	Actual* ( <i>n</i> = 21)	12 (57.1)	16 (76.2)	7 (33.3)
	Preferred† ( <i>n</i> = 61)	39 (63.9)	48 (78.7)	37 (60.7)
Ward nurse	Actual* ( <i>n</i> = 21)	1 (4.8)	20 (95.2)	0 (0)
	Preferred† ( <i>n</i> = 58)	16 (27.6)	49 (84.5)	8 (13.8)
Other	Actual* ( <i>n</i> = 8)	3 (37.5)	1 (12.5)	7 (87.5)
	Preferred† ( <i>n</i> = 8)	3 (37.5)	3 (37.5)	7 (87.5)
Gastroenterologist	Actual* ( <i>n</i> = 12)	4 (33.3)	7 (58.3)	6 (50.0)
	Preferred† ( <i>n</i> = 49)	27 (55.1)	28 (57.1)	18 (36.7)
IBD specialist nurse	Actual* ( <i>n</i> = 12)	7 (58.3)	7 (58.3)	6 (50.0)
	Preferred† ( <i>n</i> = 39)	25 (64.1)	24 (61.5)	20 (51.3)
Community nurse	Actual* ( <i>n</i> = 8)	0 (0)	1 (12.5)	7 (87.5)
	Preferred† ( <i>n</i> = 29)	8 (27.6)	8 (27.6)	26 (89.7)
GP	Actual* ( <i>n</i> = 3)	2 (66.7)	0 (0)	2 (66.7)
	Preferred† ( <i>n</i> = 51)	15 (29.4)	6 (11.8)	43 (84.3)

GP, general practitioner; IBD, inflammatory bowel disease.

\*When was dietary advice provided?

†When would you have liked dietary advice to be provided?

‡Not including that of registered support associations or stoma product suppliers.

received advice on how to prepare certain foods (71.4% *vs* 30.6%). Nearly all in group 1 who received dietary advice reported making changes based on this advice compared to just over three-quarters in group 2 (95.9% *vs* 77.8%).

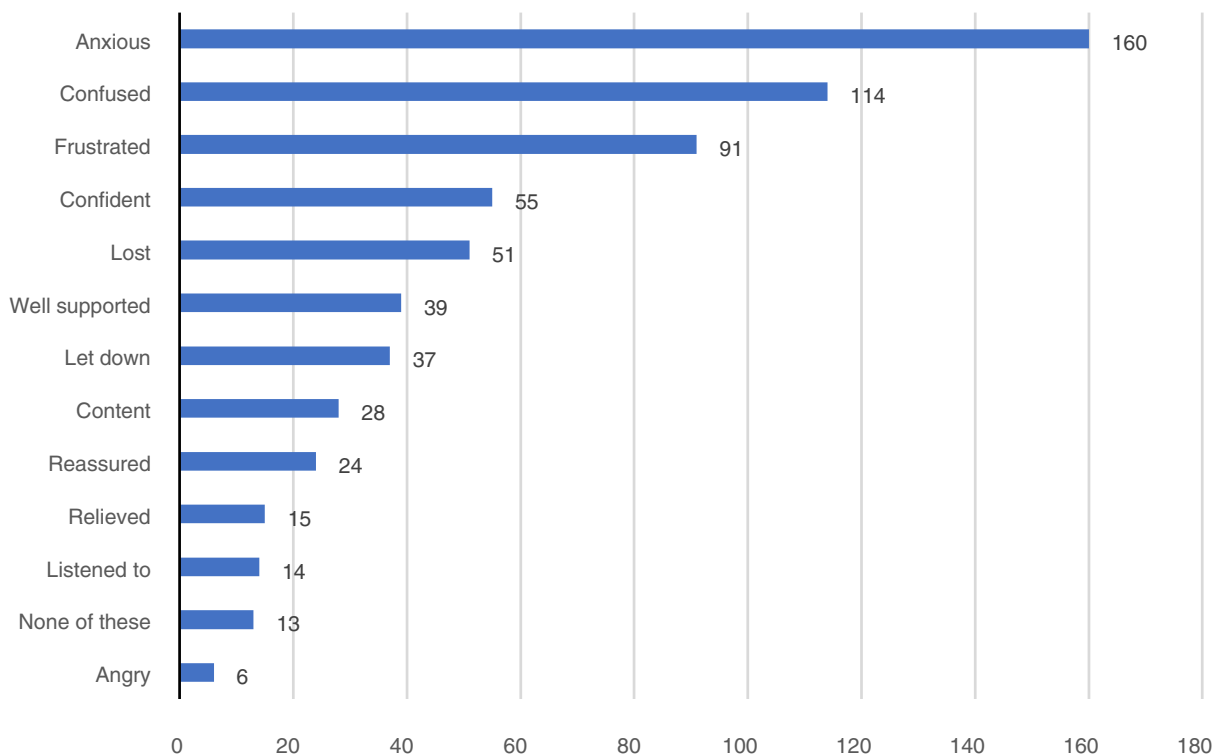
## Discussion

Our survey identifies a need for improved provision of dietary advice for people with an ileostomy. Almost one-third of respondents had never received dietary advice for their ileostomy, but most would have liked it. A recent UK-based study of people with an output stoma of any type reported similar findings [13], suggesting that provision of dietary advice is not universal.

Feelings of anxiety, and to a lesser extent confusion and frustration, regarding diet among people with a new ileostomy were common and very few felt confident or well supported. Thus, there is an unmet need for high-quality dietary advice for people with ileostomies. HCPs working with people with an ileostomy should work to ensure that dietary advice is fully embedded within care pathways and that the advice and support is clear, relevant and consistent.

We found a widespread problem with conflicting advice, which is similar to reports from qualitative studies of conflicting or confusing dietary advice among people with Crohn's disease and an ileostomy [10], and dissatisfaction with preoperative advice regarding appropriate dietary choices for people with a stoma [16]. It is





**Figure 2** How did/do you feel about managing your diet with a new ileostomy? Select up to three options.

**Table 5** Questions relating to patient satisfaction with dietary advice ( $n = 201$ ).

	Extremely <i>n</i> (%)	Fairly <i>n</i> (%)	Slightly <i>n</i> (%)	Not at all <i>n</i> (%)
How confident were you in the dietary advice?	23 (11.4)	101 (50.2)	57 (28.4)	20 (10.0)
How useful was the dietary advice?	44 (21.9)	93 (46.3)	53 (26.4)	11 (5.5)
How satisfied were you with the dietary advice?	32 (15.9)	93 (46.3)	59 (29.4)	17 (8.5)

perhaps unsurprising that people with an ileostomy often experience conflicting advice since evidence to inform practice is limited and advice is primarily informed by experience and expert opinion [12,17]. Provision of appropriate advice is complicated by individual variation due to differences in length and health of functioning intestine, sometimes in addition to independent comorbidities such as diabetes [18,19]. High-quality research evaluating dietary interventions for people with an ileostomy is a priority to establish evidence to inform best practice for dietary management and provision of dietary advice. Quality, and appropriate personalization, of dietary advice could be further improved if all HCPs who support people with an ileostomy were to undertake appropriate training, assessment and continuing professional development.

This would ensure a comprehensive understanding of the anatomical and physiological impact of ileostomy surgery for different conditions, and awareness of the evidence-base to underpin the dietary advice they provide.

Common problems experienced by respondents included loose output, gas and high output, and dietary changes were reported as beneficial to ileostomy management by around half of respondents who received advice. Others may have felt their issues were not related to diet or that the dietary advice they received was not helpful. Previous studies investigating whether having an ileostomy affects dietary choices have shown that the extent and type of dietary modification is variable. Furthermore, many people with an ileostomy continue a normal diet without apparent adverse

consequence [2,20–22]. Appropriate dietary advice is particularly important for people with an ileostomy due to the nutritional risks associated with the loss of colon and changes in small intestine length and/or physiology, in conjunction with potential nutritional risks of dietary restriction for the purpose of managing consequences of their intestinal surgery [23,24]. In the weeks following ileostomy surgery, the remaining small intestine heals and adapts to the loss of the colon by increasing absorption of water and electrolytes [25]. Appropriate patient follow-up and support is needed, and dietary advice should be reviewed and adapted over time.

Stoma nurses were the main source of dietary advice, and the most preferred source of advice. However, many respondents wanted dietary advice from a dietitian while relatively few received this. In practice, all individuals having ileostomy surgery will see a surgeon and usually a stoma nurse, while only some will be referred to a dietitian [26], e.g. if there is a specific problem such as high output [27]. This is unlikely to change dramatically, at least in the near future, as National Health Service (NHS) dietetics services do not have sufficient resources to provide advice to all people with an ileostomy. Multidisciplinary working is essential to establish local consensus on what and how dietary advice should be provided to people with an ileostomy, to improve clarity and confidence in dietary management. One solution might be for stoma nurses and dietitians to collaboratively produce printed dietary advice for people with an ileostomy, ideally also in liaison with colorectal surgeons. This would improve consistency in dietary advice and give people with an ileostomy confidence that dietitians have been involved in developing this advice. Alternatively, this could be achieved on a national level if professional (e.g. Association of Coloproctology of Great Britain and Ireland) and patient organizations (e.g. the Ileostomy and Internal Pouch Association) work together with the British Dietetic Association to develop such guidance. It could then be made accessible not only to stoma nurses, surgeons and people with an ileostomy, but also to general practitioners and other HCPs involved in supporting people with an ileostomy. The provision of high-quality, and ideally evidence-based, dietary advice may ultimately improve levels of satisfaction with advice. Almost two-thirds of the respondents who received dietary advice were at least fairly satisfied with the advice, but there is still much room for improvement.

Comparison of responses from people living with an ileostomy for < 6 months *vs* > 10 years suggested that provision of dietary advice may be more common now than in the past. It is possible that some of the differences seen are due to difficulty recalling experiences

from > 10 years ago compared to the last 6 months. However, an increase was seen in the proportion of people receiving dietary advice from a stoma nurse which may be due to improved access to stoma nurses in the NHS over recent decades [28]. As expected, social media were a more common source of dietary advice for those with recent ileostomy formation.

Respondents expressed a desire for dietary advice to be more frequently provided prior to surgery. However, it was previously suggested that patients feel overwhelmed with the amount of information received prior to colorectal surgery [16], and taking in additional information at this stressful time may be difficult. Special menus and verbal advice on making meal choices in hospital after ileostomy surgery were areas where patient needs were not met, and very few felt they received sufficient support in making meal choices. This may be due to organizational factors such as lack of training and time for ward staff. Staff training and development of ward protocols, including communication on individual patient dietary requirements and provision of special menus, by stoma nurses and dietitians for, and in collaboration with, surgical ward staff are probably key to improving support with meal choices in hospital following ileostomy surgery.

This survey has several strengths. To our knowledge, it is the first to investigate sources and format of dietary advice for people with an ileostomy. It also shows preferences regarding where and how they would like to receive dietary advice. A major strength was the use of cognitive interviews and collaboration with a wide range of stakeholders when designing the questionnaire [14]. This increased face validity, reducing the risk of respondents misinterpreting questions and responses, and ensured questions were relevant and comprehensive.

This study also has some limitations. Although we engaged with a wide range of stakeholders in the development of the questionnaire, it is possible that some relevant questions were not asked, that some response options were not broad enough, or some terms may not have been interpreted the same way by all respondents. Most respondents (72.5%) were women, whereas Hospital Episodes Statistics suggest that  $\approx 47\%$  of ileostomies are in women [29]. Over-representation of women is common in studies where surveys are the primary data collection method [30]. In addition, it is possible that self-selection bias may have resulted in responders with more ileostomy-related problems than non-responders, and perhaps more interested in diet.

All regions of Great Britain were well represented; however, small numbers of respondents from Northern Ireland and the Republic of Ireland may limit generalizability to these countries. A wide range of ages was represented, although there were fewer responses in the

16–24 year age group, reflecting the smaller proportion of ileostomy surgeries performed in this age range [29]. Older adults  $\geq 75$  years were under-represented, perhaps because social media were the primary mode of survey distribution [29].

## Conclusions

Our findings suggest that there is an unmet need for high-quality dietary advice among people who undergo ileostomy surgery. Anxiety about managing diet with a new ileostomy is common. Stoma nurses are the main source of dietary advice, but it may be received from a wide range of sources and is often perceived as conflicting. Dietary advice and support need to be clear and consistent between HCPs to alleviate concerns. This could be achieved through collaboration between relevant professional and patient organizations to produce agreed guidelines for the dietary management and support of people with an ileostomy.

## Acknowledgements

We are very grateful to the Ileostomy and Internal Pouch Association, particularly Scott Clifford, and Crohn's and Colitis UK for promoting the survey online. Also, we owe thanks to members of our PPI group, particularly those who participated in the development of the questionnaire, to all the people living with an ileostomy who took the time to complete the survey, and to Dr Aidan Searle for his support during the study.

## Conflicts of interest

The authors have received funding for a related study (of healthcare professionals' perceptions of the dietary advice they provide for people with an ileostomy) from the Ileostomy and Internal Pouch Association.

## Author contributions

AM: Substantial contribution to concept and design of the study, acquisition, analysis and interpretation of data. Drafted article and approved final version submitted. CE: Substantial contribution to concept and design of the study, and interpretation of data. Revised draft article critically for important intellectual content. Approved final version submitted. CA: Substantial contribution to concept and design of the study, and interpretation of data. Revised draft article critically for important intellectual content. Approved final version submitted. All authors above agree to be accountable for all aspects of the work in ensuring that questions

related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

## Funding

This study was funded by the NIHR Biomedical Research Centre at University Hospitals Bristol and Weston NHS Foundation Trust and the University of Bristol. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

## Ethics approval

Ethical approval was obtained from the Faculty of Health Sciences Research Ethics Committee at the University of Bristol (reference number 73467).

## References

- 1 Elliston T, Rolls N, James-Reid S, Kane M. *Excellence in stoma care – the value of stoma care nurse specialists*. Peterborough: Coloplast Limited; 2019 [Feb 2020]. [https://www.coloplast.co.uk/Global/UK/Stoma/HCP/Excellence\\_in\\_Stoma\\_Care\\_Final.pdf](https://www.coloplast.co.uk/Global/UK/Stoma/HCP/Excellence_in_Stoma_Care_Final.pdf) (accessed February 2020).
- 2 de Oliveira AL, Boroni Moreira AP, Pereira Netto M, Gonçalves Leite IC. A cross-sectional study of nutritional status, diet, and dietary restrictions among persons with an ileostomy or colostomy. *Ostomy Wound Manage* 2018; **64**: 18–29.
- 3 Leong APK, Londono-Schimmer EE, Phillips RKS. Life-table analysis of stomal complications following ileostomy. *Br J Surg* 1994; **81**: 727–9.
- 4 Cronin E. Dietary advice for patients with a stoma. *Gastrointestinal Nursing* 2013; **11**: 14–24.
- 5 Burch J. Nutrition for people with stomas. 2: An overview of dietary advice. *Nurs Times* 2008; **104**: 26–7.
- 6 Goodey A, Colman S. Safe management of ileostomates with high-output stomas. *Br J Nurs* 2016; **25**: S4–S9.
- 7 Dorman C. Ostomy basics. *RN* 2009; **72**: 22–7.
- 8 Davidson F. Quality of life, wellbeing and care needs of Irish ostomates. *Br J Nurs* 2016; **25**: S4–12.
- 9 Jansen F, van Uden-Kraan CF, Braakman JA, van Keizer-swaard PM, Witte BI, Verdonck-de Leeuw IM. A mixed-method study on the generic and ostomy-specific quality of life of cancer and non-cancer ostomy patients. *Support Care Cancer* 2015; **23**: 1689–97.
- 10 Morris A, Leach B. Exploring individuals' experiences of having an ileostomy and Crohn's disease and following dietary advice. *Gastrointestinal Nursing* 2015; **13**: 36–41.
- 11 Persson E, Gustavsson B, Hellström A-L, Lappas G, Hultén L. Ostomy patients' perceptions of quality of care. *J Adv Nurs* 2005; **49**: 51–8.
- 12 Mitchell A, Perry R, England C, Searle A, Atkinson C. Dietary management in people with an ileostomy: a

- scoping review protocol. *JBIC Database System Rev Implementation Rep* 2019; **17**: 129–36.
- 13 Beeken RJ, Haviland JS, Taylor C *et al*. Smoking, alcohol consumption, diet and physical activity following stoma formation surgery, stoma-related concerns, and desire for lifestyle advice: a United Kingdom survey. *BMC Public Health* 2019; **19**: 574.
  - 14 Drennan J. Cognitive interviewing: verbal data in the design and pretesting of questionnaires. *J Adv Nurs*. 2003; **42**: 57–63.
  - 15 Eysenbach G. Improving the quality of web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *J Med Internet Res* 2004; **6**: e34.
  - 16 Short V, Atkinson C, Ness AR, Thomas S, Burden S, Sutton E. Patient experiences of perioperative nutrition within an enhanced recovery after surgery programme for colorectal surgery: a qualitative study. *Colorectal Dis* 2016; **18**: O74–80.
  - 17 Baker M. Food for thought: re-evaluating dietary advice. *Gastrointestinal Nursing* 2015; **13**: 14–5.
  - 18 Fulham J. Providing dietary advice for the individual with a stoma. *Br J Nurs* 2008; **17**: S22–7.
  - 19 Medlin S. Nutritional and fluid requirements: high-output stomas. *Br J Nurs* 2012; **21**: S22–5.
  - 20 Richbourg L. Food fight: dietary choices made by people after stoma formation. *Gastrointestinal Nursing* 2012; **10**: 44–50.
  - 21 Bingham S, Cummings JH, McNeil NI. Diet and health of people with an ileostomy. 1. Dietary assessment. *Br J Nutr*. 1982; **47**: 399–406.
  - 22 Thomson TJ, Runcie J, Khan A. The effect of diet on ileostomy function. *Gut* 1970; **11**: 482–5.
  - 23 Chan DKH, Ng J, Koh FH-X *et al*. Journey for patients following ileostomy creation is not straightforward. *Int J Colorectal Dis* 2019; **34**: 2075–80.
  - 24 Arenas Villafranca JJ, López-Rodríguez C, Abilés J, Rivera R, Gándara Adán N, Utrilla NP. Protocol for the detection and nutritional management of high-output stomas. *Nutr J* 2015; **14**: 45.
  - 25 Rowe KM, Schiller LR. Ileostomy diarrhea: pathophysiology and management. *Proc (Bayl Univ Med Cent)* 2020; **33**: 218–26.
  - 26 Bracey E, Mortensen N. Pouches and stomas. *Medicine* 2015; **43**: 308–13.
  - 27 Slater R. High-output stomas: challenges with a large laparotomy wound. *Br J Nurs* 2012; **21**: S26–33.
  - 28 White M. The rise of the stoma care nurse. *Br J Nurs* 2017; **26**: S15–S.
  - 29 NHS digital. Hospital admitted patient care activity, 2017–18. <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity/2017-18> (accessed November 2018).
  - 30 Smith G. Does gender influence online survey participation?: a record-linkage analysis of university faculty online survey response behavior. ERIC Document Reproduction Service No ED 501717. 2008.

## Supporting Information

Additional Supporting Information may be found in the online version of this article:  
Appendix S1. Survey of dietary advice for people with an ileostomy: supplementary material.